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ABSTRACT

This document consists of the nine issues of the journal "Exceptional Parent" published during 1993. This journal contains articles particularly aimed at parents of children with disabilities. Major articles published during this period are the following: "Annual Guide to Products and Services"; "Coping with Incontinence" (Katherine F. Jeter); "Annual Income Tax Guide"; "Finding Funding for Assistive Technology"; "Insurance Claim Appeal" (Ryan J. Whitlow); "Adventures in Camping" (Ellen Coe); "Tough Choice" (Carole Briggs Ayres); "Recreation Resource Section"; "Evaluating Feeding Concerns" (Ellen H. King); "Health Care Reform" (David J. Dunn); "Aquatic Sports"; "Family Support Programs Are Growing"; "Inclusion" (from a parent's, a child's, an administrator's, and a U.S. Senator's perspectives); "Parent-Teacher Cooperation--A Shared Responsibility" (Priscilla H. Presley); "Residential Placement: Coping with Separation" (Karen Cord Taylor); "Choosing Holiday Toys"; "Health Care Reform: Getting to the Heart of the Matter" (William Sciarillo); "Purchasing a Hearing Aid"; "Update on School Bus Safety" (Roseann Schwaderer); "New Technology for Artificial Arms"; "Getting Started with Computers"; "Alliance for Technology Access Directory"; and "Technology Use at Home." (DB)

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Exceptional Parent
Volume 23 Numbers 1-9

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Exceptional Parent

January 1993

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Exceptional Parent



January 1993

Volume 23, Number 1

Welcome to *Exceptional Parent's* 1993 Annual Guide to Products and Services — a bonus issue for all our subscribers.

Exceptional Parent readers are consumers who want to be as knowledgeable about the products and services they will be purchasing as well as those prescribed by physicians, therapists and other health care or education professionals. The 1993 Annual Guide to Products and Services provides easy access to hundreds of manufacturers and service providers. It also contains valuable resource sections.

Parents of children with disabilities have created the need for this guide! They have played an important role in the "consumer's revolution" of the past two decades. They have developed increasing abilities and confidence in making decisions about all areas in the lives of their children. They have also become active participants in the decision-making process regarding special products and services to facilitate their children's participation in everyday life.

When we first started *Exceptional Parent* in 1971, parents told us how difficult it was to get straightforward information about products and services. Parents had to depend entirely upon professionals who usually told parents about a few specific products or services and rarely described alternative options. At the same time, manufacturers of products and providers of services did not have direct ways of communicating with parents.

We are proud of the role *Exceptional Parent* has played — via articles, directories and advertising — in changing the relationship between manufacturers and medical equipment professionals and parents in the selection of products and services. Today, parents are active participants.

Stanley D. Klein, Ph.D.

Maxwell J. Schleifer, Ph.D.

Co-Founders, Publishers

TABLE OF CONTENTS

- 7 Parent Training & Information Centers
- 9 Assistive Technology Centers
- 40 Federal Agencies

- 42 Wheelchair Accessible Theme Parks
- 44 Wheelchair Accessible National Parks

- 11 Augmentative Comm. & Evaluation
- 12 Bathroom Equipment
- 13 Bedding
- 13 Catalogs
- 14 Clothing
- 15 Communication Aids
- 15 Computer Hardware
- 16 Computer Software
- 16 Environmental Controls

- 18 Estate Planning
- 18 Feeding Aids
- 18 Food, Special
- 18 Headgear
- 18 Hearing Aids, Equipment
- 19 Home Health Care
- 19 Incontinence
- 20 Personal Care
- 20 Publishers

- 20 Ramps/Lifts
- 23 Recreation
- 32 Schools, Camps & Residences
- 24 Seating/Positioning
- 26 Standing Equipment
- 26 Toys and Hobbies
- 26 Vans/Van Conversion/Driving Aids
- 27 Vision Aids
- 28 Wheelchairs

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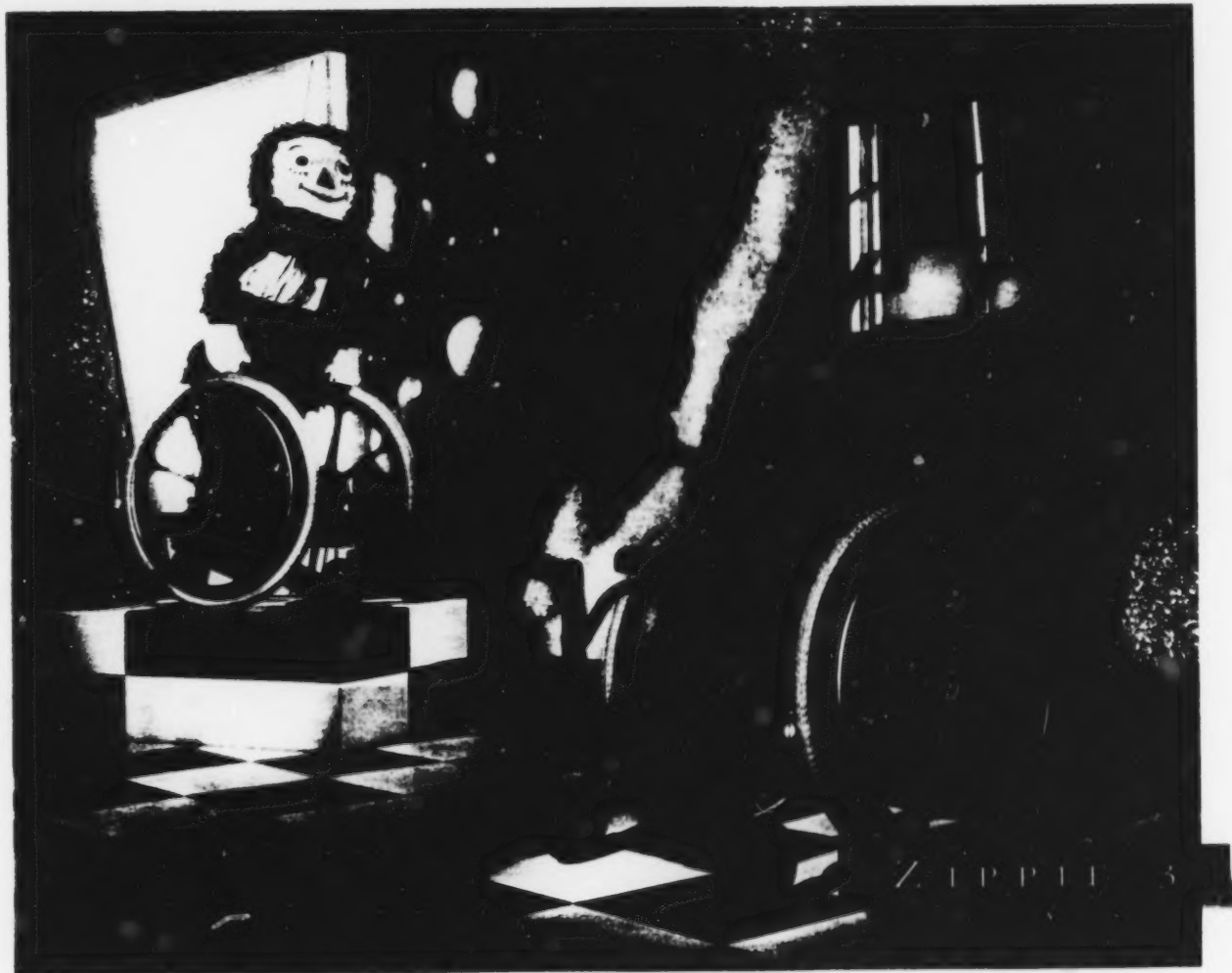
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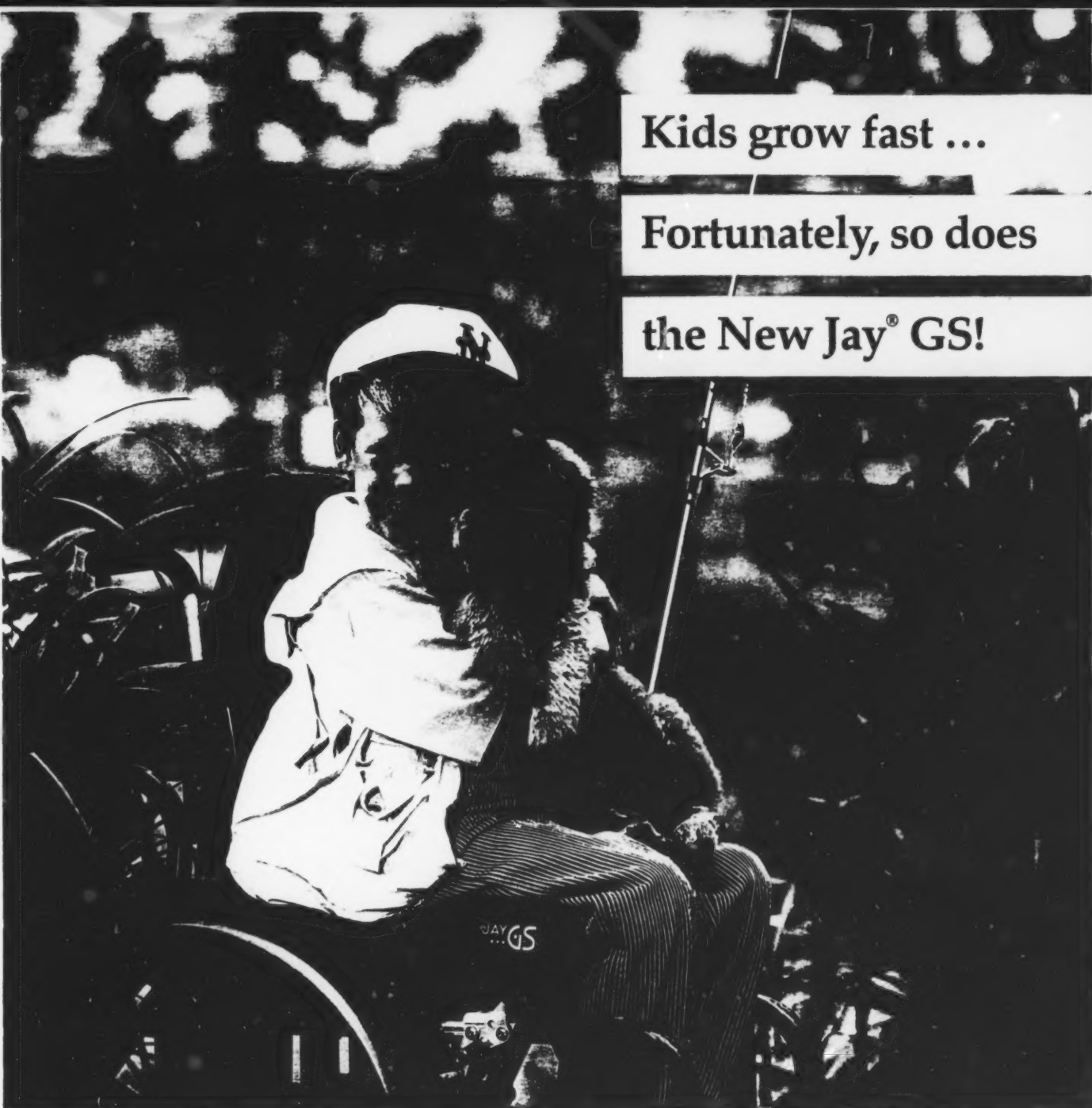
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continued on page 8

continued from page 7

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Albuquerque, NM 87102
(800) 524-5176 (in NM)
(505) 842-9045

New York

Advocates for Children
24-16 Bridge Plaza S
Long Island City, NY 11101
(718) 729-8866
(Voice/TDD)

Parent Network Center, Inc.
1443 Main St.
Buffalo, NY 14209
(800) 724-7408 (in NY)
(716) 885-1004
(716) 885-3527 (TDD)

Resources for Children with Special Needs
Project Staff
200 Park Ave. S
Suite 816
New York, NY 10003
(212) 677-4650

North Carolina

Exceptional Children's Assistance Center
P.O. Box 16
Davidson, NC 28036
(704) 892-1321

Families First Coalition, Inc.
300 Enola Rd.
Morganton, NC 28655
(704) 433-2661

North Dakota

Pathfinder Parent Training and Information Center
1600 Second Ave. SW
Minot, ND 58701
(701) 852-9426

Ohio

Child Advocacy Center
SOC Information Center
106 Wellington Place
Cincinnati, OH 45219
(513) 381-2400 (TTY)

Ohio Coalition for the Education of Handicapped Children
1299 Campbell Rd., Suite B
Marion, OH 43302
(614) 431-1307
(Voice/TDD)

Oklahoma

Pro-Oklahoma
UCP of Oklahoma
1917 S. Harvard Ave.
Oklahoma City, OK 73128
(800) PL94-142
(405) 681-9710

Oregon

Oregon COPE Project, Inc.
999 Locust St. NE, Box B
Salem, OR 97303-5299
(503) 373-7477
(Voice/TDD)

Pennsylvania

Parent Education Network
333 E. Seventh Ave.
York, PA 17404
(717) 845-9722

Parents Union for Public Schools
311 S. Juniper St., Suite 602
Philadelphia, PA 19107
(215) 546-1212

Puerto Rico

Asoc. de Padres Por Bienestar de Niños Impedidos de PR
P.O. Box 21301
Rio Piedras, PR 00928
(809) 763-4665
(809) 765-0345

Rhode Island

Rhode Island Parent Information Network
500 Prospect St.
Pawtucket, RI 02860
(401) 831-3150

South Carolina

Parents Reaching Out to Parents of S.C.
2712 Middleburg Dr.
Suite 102
Columbia, SC 29240
(803) 734-3547

South Dakota

South Dakota Parent Connection, Inc.
Nancy Nelson
P.O. Box 84118-4813
Sioux Falls, SD 57118
(800) 640-4553 (in SD)
(605) 335-8844

Tennessee

Support and Training for Exceptional Parents
1805 Hayes St., Suite 100
Nashville, TN 37203
(615) 327-0294

Texas

Fiesta Educativa
P.O. Box 2579
Laredo, TX 78041
(512) 722-5174

PATH
6465 Calder
Suite 202
Beaumont TX 77706
(800) 678-9638
(409) 866-4726

Utah

Utah Parent Center
2290 East 4500 South
Suite 110
Salt Lake City, UT 84117
(800) 468-1160 (in UT)
(801) 272-1051

Vermont

Vermont Information and Training Network
Champlain Mill
Winooski, VT 05404
(802) 655-4016
(Voice/TDD)

Virginia

Parent Educational Advocacy Training Center
228 S. Pitt St., Room 300
Alexandria, VA 22314
(800) 869-6782 (in VA, WV & MD)
(703) 836-2953
(703) 836-3026 (TDD)

Washington

Specialized Training of Military Parents (STOMP)
12208 Pacific Highway SW
Tacoma, WA 98499
(206) 588-1741

Washington PAVE
6316 South 12th
Tacoma, WA 98465
(800) 5-PARENT (in WA, Voice/TDD)
(206) 565-2266 (Voice/TDD)

West Virginia

West Virginia Parent Training and Information Center
Schroath Building, Suite I
229 Washington Ave.
Clarksburg, WV 26301
(800) 281-1436
(304) 624-1436

Wyoming

Wyoming Parent Information Center
270 Fort St.
Buffalo, WY 82834
(307) 684-5461

NPND Invites You to Join

Mission

The National Parent Network on Disabilities (NPND) works to serve the parents and family members of persons with disabilities, regardless of the type of disability.

Membership Fees

Parent/Individual with a Disability	\$25
<i>(Stipend Available)</i>	
Professionals	\$40
Parent Group	\$50
Affiliated Organization	\$100
Contributor	\$1,000
Corporation	\$1,000
Sustaining	\$3,000
Parent Coalition - Voting	\$*

*Sliding Scale - Call NPND for details

Please send your check, along with your name and full address, including phone numbers, made payable to: **The National Parent Network on Disabilities, 1600 Prince Street, Suite 115, Alexandria, Virginia 22314, (703) 684-6763.**

RESOURCE SECTION

Assistive Technology Centers

The following is a state-by-state listing of centers offering technology-related assistance to people with disabilities. We have compiled an integrated list of centers affiliated with RESNA, an interdisciplinary association for the advancement of rehabilitation and assistive technologies, and the Alliance for Technology Access (ATA), a national network of community-based computer resource centers and technology businesses. RESNA-affiliated centers receive funding under the "Tech Act" or PL 100-407, the Technology-Related Assistance for Individuals with Disabilities Act of 1988. A total of 42 states have now received Tech Act federal grants to develop statewide consumer-responsive systems to provide assistive technology information and training to individuals with disabilities and their families.

Key to Section ✓ = RESNA CENTERS ☆ = ATA CENTERS

NATIONAL OFFICES:

- ✓ RESNA
1101 Connecticut Ave. NW
Suite 700
Washington, D.C. 20036
(202) 857-1140 (Voice/TDD)

Alliance for Technology
Access
1307 Solano Ave.
Albany, CA 94706-1888
(510) 528-0746

ALABAMA

- ☆ Birmingham Alliance for
Technology Access Center
Birmingham Independent
Living Center
206 13th Street South
Birmingham, AL 35233-1317
(205) 251-2223
AppleLink: BILC

- ☆ Technology Assistance
for Special Consumers
P.O. Box 443
Huntsville, AL 35804
(205) 532-5996
AppleLink: TASC

ALASKA

- ☆ Alaska Ctr. for Adaptive Tech.
700 Katlian, Ste. B
Sitka, AK 99835
(800) 478-6962 (in AK)
(907) 747-6962
AppleLink: ACAT
- ✓ Assistive Tech. of Alaska
Div. of Vocational Rehab.
400 D Street, Ste. 230
Anchorage, AK 99501
(907) 274-0138

ARKANSAS

- ✓ Increasing Capabilities
Access Network (ICAN)
Dept. of Human Services
Div. of Rehab. Services
2201 Brookwood, Ste. 117
Little Rock, AR 72202
(501) 666-8868

- ☆ Technology Resource Ctr.
c/o Arkansas Easter Seal
Society
2801 Lee Ave.
Little Rock, AR 72205
(501) 663-8331
AppleLink: TRC

CALIFORNIA

- Computer Access Center
2425 16th Street
Room 23
Santa Monica, CA 90405
(310) 450-8827
AppleLink: CAC.SM

- DCCG: Tech. Resources
for People with Disabilities
2547 Eighth Street, 12-A
Berkeley, CA 94710-2572
(510) 841-3224
AppleLink: DCCG

- ☆ Special Awareness
Computer Center
Rehabilitation Center
2975 N. Sycamore Dr.
Simi Valley, CA 93065
(805) 582-1881
AppleLink: SACC

- ☆ Special Technology Center
590 Castro St.
Mountain View, CA 94041
(415) 961-6789
AppleLink: STC

- ☆ TASK
Team of Advocates
for Special Kids
100 W. Cerritos
Anaheim, CA 92805-6546
(714) 533-TASK
AppleLink: TASK

COLORADO

- ☆ Access Ability Resource
Center
1056 East 19th Avenue
B-410
Denver, CO 80218-1088
(303) 861-6250
AppleLink: AARC

- ✓ Colorado Assistive
Technology Project
Rocky Mountain Resource
and Training Institute
6355 Ward Rd., Ste. 310
Arvada, CO 80004
(800) 444-2942

CONNECTICUT

- ✓ Connecticut State
Dept. of Human Resources
Bureau of Rehab. Services
1049 Asylum Ave.
Hartford, CT 06105
(203) 566-3318

DELAWARE

- ✓ Delaware Assistive
Technology Initiative
Applied Science and
Engineering Laboratories
University of Delaware/
Alfred I. DuPont Institute
P.O. Box 269
Wilmington, DE 19899
(302) 651-6834

FLORIDA

- ☆ Computer CITE
(Center for Independent
Technology and Education)
215 E. New Hampshire St.
Orlando, FL 32804
(407) 898-2483
AppleLink: CITE

- ✓ Florida Department of
Labor and Employment
Div. of Vocational Rehab.
Bureau of Client Services
Rehab. Engineering Tech.
1709-A Mahan Dr.
Tallahassee, FL 32399-0696
(904) 488-6210

GEORGIA

- ✓ Georgia Assistive Tech. Prog.
Div. of Rehabilitation Svcs.
Dept. of Human Resources
878 Peachtree St. NE
Room 712
Atlanta, GA 30309
(404) 894-7593

- ☆ Tech-Able
1040 Irwin Bridge Rd.
Conyers, GA 30207
(404) 922-6768
AppleLink: TECHABLE

HAWAII

- ☆ Aloha Special Technology
Access Center
1750 Kalakaua Ave., #1008
Honolulu, HI 96826-3725
(808) 955-4464
AppleLink: ALOHASTAC

- ✓ HATS (Hawaii Assistive
Technology Services)
Dept. of Human Services
677 Ala Moana Blvd., #403
Honolulu, HI 96813
(808) 532-7110

IDAHO

- ✓ Idaho State Program for
Technology-Related
Assistance for People
with Disabilities
Univ. of Idaho — Prof. Bldg.
Idaho Center on
Developmental Disabilities
129 W. Third St.
Moscow, ID 83843
(208) 885-6849

ILLINOIS

- ✓ Illinois Technology-Related
Assistance Project for
Individuals of All Ages with
Disabilities
Illinois Dept. of Rehab. Svcs.
411 E. Adams
Springfield, IL 62701
(217) 522-7985

- ☆ Northern Illinois Center
for Adaptive Technology
3615 Louisiana Rd.
Rockford, IL 61108-6195
(815) 229-2163
AppleLink: ILCAT

- ☆ Technical Aids & Assistance
for the Disabled Center
1950 W. Roosevelt
Chicago, IL 60608
(312) 421-3373
AppleLink: TAAD

INDIANA

- ✓ Indiana ATTAIN Project
Indiana Family and Social
Services Administration
402 W. Washington, #W453
P. O. Box 7083
Indianapolis, IN 46207-7083
(317) 233-3394

IOWA

- ✓ Iowa Program for
Assistive Technology (IPAT)
Iowa Univ. Affiliated Prog.
University Hospital School
Iowa City, IA 52242
(319) 353-6386

KANSAS

- ☆ Technology Resources for
Special People
3023 Canterbury
Salina, KS 67401
(913) 827-0301
AppleLink: TRSP

continued on page 10

RESOURCE SECTION

continued from page 9

KENTUCKY

- ☆ Blue Grass Technology Ctr. for People with Disabilities
169 N. Limestone
Lexington, KY 40507
(606) 255-9951
AppleLink: BLUEGRASS
- ☆ Disabled Citizens Computer Center
Louisville Free Public Library
Fourth and York Streets
Louisville, KY 40203-2257
(502) 561-8637
AppleLink: DCCC
- ✓ Kentucky Assistive Technology Service (KATS) Network
Kentucky Dept. for the Blind
427 Versailles Rd.
Frankfort, KY 40601
(800) 327-5287 (in KY)
(502) 564-4665
- ☆ SpecialLink
36 W. Fifth St.
Covington, KY 41011
(606) 491-2464
AppleLink: SPECIALINK

LOUISIANA

- ☆ CATER —
Ctr. for Adaptive Tech. and Educational Resources
4232 Division St., Ste. 110-B
Metairie, LA 70002
(504) 888-5248/0163
AppleLink: CATER
- ✓ Louisiana Assistive Technology Project
Louisiana Planning Council on Developmental Dis.
P. O. Box 3455, Mail Bin 14
Baton Rouge, LA 70821
(504) 342-6804

MAINE

- ✓ Maine CITE (Coordinating Center for Consumer Information and Technology Training Exchange)
Department of Educational and Cultural Services
Univ. of Maine at Augusta
University Heights
Augusta, ME 04330
(207) 621-3195
- ☆ Maine Parent Federation
P.O. Box 2067
Augusta, ME 04338-2067
(207) 582-2504
AppleLink: MPF

MARYLAND

- ☆ Learning Independence Through Computers, Inc.
28 E. Ostend St.
Suite 140
Baltimore, MD 21230
(410) 659-5462
AppleLink: LINC
- ✓ Maryland Technology Assistance Program (TAP)
Governor's Office for Handicapped Individuals
300 W. Lexington St., Box 10
Baltimore, MD 21201
(410) 333-3098

MASSACHUSETTS

- ✓ Massachusetts Assistive Technology Partnership (MATP) Center
Commission for the Deaf
Gardner 529
Children's Hospital
300 Longwood Avenue
Boston, MA 02116
(617) 735-7820/7301 (TDD)
- ☆ Massachusetts Special Technology Access Center
12 Mudge Way 1-6
Bedford, MA 01730-2138
(617) 275-2446
AppleLink: MASTAC

MICHIGAN

- ☆ Living & Learning Resource Centre
Physically Impaired Assoc. of Michigan
601 W. Maple St.
Lansing, MI 48906-5038
(800) 833-1996 (in Mich.)
(517) 487-0883
AppleLink: LLRCPIAM
- ✓ Michigan Dept. of Education Rehab. Services
P.O. Box 30010
Lansing, MI 48909
(517) 373-3391

MINNESOTA

- ✓ Minnesota STAR Program
Governor's Advisory Council on Technology for People with Disabilities
300 Centennial Building
685 Cedar St.
St. Paul, MN 55155
(612) 297-1554
- ☆ PACER Center, Inc.
4826 Chicago Ave. S
Minneapolis, MN 55417
(612) 827-2966 (Voice/TDD)
AppleLink: PACER.CTR

MISSISSIPPI

- ✓ Mississippi Project START — Success Through Assistive/Rehabilitation Technology
Division of Rehabilitation Services
P. O. Box 1000
Jackson, MS 39215-1000
(601) 354-6891

MISSOURI

- ✓ Missouri Assistive Technology Project
University of Missouri — Kansas City
School of Education
5100 Rockhill Rd.
Kansas City, MO 64110
(816) 235-5337
- ☆ Technology Access Center
12110 Clayton Rd.
St. Louis, MO 63131-2599
(314) 569-8404/8100
AppleLink: TACSTL

MONTANA

- ✓ Montech
Rural Institute on Disabilities
Dept. of Social and Rehabilitation Services
The University of Montana
Human Dev. Ctr.
634 Eddy Ave.
Missoula, MT 59812
(406) 243-4597
- ☆ Parents, Let's Unite for Kids
1500 North 30th St. #2
Billings, MT 59101-0298
(406) 657-2055
AppleLink: PLUK

NEBRASKA

- ✓ Nebraska Assistive Technology Project
Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509
(402) 471-0735

NEVADA

- ✓ Assistive Tech. Project
Rehabilitation Division
PRPD
505 E. King St.
Room 502
Carson City, NV 89710
(702) 687-4452
- ☆ Nevada Technology Center
2860 E. Flamingo Rd.
Suite I
Las Vegas, NV 89121
(702) 735-2922
AppleLink: NTC

NEW HAMPSHIRE

- ✓ New Hampshire Assistive Tech. Partnership Project
Institute on Disability
The Concord Center
Ten Ferry St., Unit #14
Concord, NH 03301
(800) 427-3338 (in NH)
(603) 224-0630

NEW JERSEY

- ☆ The Ctr. for Enabling Tech.
9 Whippany Rd.
P.O. Box 272
Whippany, NJ 07981-0272
(201) 428-1455
AppleLink: CET
- ☆ Computer Center for People with Disabilities
c/o Family Resource Assoc.
35 Haddon Ave.
Shrewsbury, NJ 07702-4007
(908) 747-5310
AppleLink: CCDA

- ✓ New Jersey Department of Labor
Office of the Commissioner
Commissioner Raymond L. Bramucci
Labor Building, CN 110
Trenton, NJ 08625
(609) 984-6550

NEW MEXICO

- ✓ New Mexico Technology-Related Assistance Program (NMTAP)
Dept. of Education
435 St. Michael Dr.
Building D
Santa Fe, NM 87505
(505) 827-3533

NEW YORK

- ✓ New York State Office of Advocate for the Disabled
TRAID (Technology-Related Assistance for Individuals with Disabilities) Project
Technology-Related Assistance for Individuals with Disabilities
1 Empire State Plaza, 10th Fl.
Albany, NY 12223-0001
(518) 473-4129 (Voice)
(518) 473-4231 (TDD)
- ☆ Techspress
Resource Center for Independent Living
409 Columbia St.
Utica, NY 13502
(315) 797-4642 (Voice/TDD)
AppleLink: TECHSPRESS

continued on page 38

ANNUAL GUIDE TO PRODUCTS & SERVICES

• Augmentative Communication

Blazie Engineering
109 E. Jarrettsville Rd.
Forest Hill, MD 21050
(410) 893-9333

Dragon Systems
320 Nevada St.
Newton, MA 02160
(617) 965-5200

Franklin Electronic Publishers, Inc.

122 Burrs Rd.
Mt. Holly, NJ 08060
(800) 762-5382 Ext. 149

The Franklin Language Master Special Edition, a fully speaking, electronic reference for people with disabilities, includes a 300,000 word dictionary, thesaurus, grammar guide, word games, and also serves as a speech augmentation device.

Gillette Children's Hospital
200 East University Ave.
St. Paul, MN 55101
(612) 291-2848

Imaginar Communication Products

307 Arizona St.
Bisbee, AZ 85603
(800) 828-1376
(602) 432-5134 (Fax)

Call or write for our free catalog of augmentative communication aids, high quality educational toys and language materials for all ages.

Innocomp
33195 Wagon Wheel
Solon, OH 44139
(800) 382-VOCA

LC Technologies
4415 Glenn Rose St.
Fairfax, VA 22032
(800) 733-5284

Vision-controlled computer - speech synthesis, environ. controls, typing, phone, games. Requires focus of one eye, nothing attached to child.

Passy-Muir Inc.

4521 Campus Dr., Ste. 273
Irvine, CA 92715
(800) 634-5397

The PM tracheostomy and ventilator speaking valves restore speech for the tracheostomized and ventilator dependent. The valves also have many secondary benefits including reduced secretions, improved swallow, sense of taste and smell and well being.

Phonic Ear, Inc.

3880 Cypress Dr.
Petaluma, CA 94954
(800) 227-0735/(707) 769-1110

A pioneer in the field: featuring innovative communication devices with DECtalk speech. Choose P.A.L.L.S. with three optional methods for easy programming; or VoisShapes, a national strategy based on simple gestures of American sign language.

Prentke Romich Company

1022 Heyl Rd.
Wooster, OH 44691
(800) 262-1984

Leader for 26 years in the delivery of quality augmentative communication devices and softwares to the non-speaking population.

Sentient Systems Technology Inc.

2100 Wharton St., Suite 630
Pittsburgh, PA 15203
(800) 344-1778

DynaVox: portable, dedicated speech aid, dynamic display, DynaSyms, DECtalk speech technology. Designed to be easy and powerful. DigiVox: lightweight recorded speech aid, 4 1/2-18 minutes speech plus more. Just call to learn more.

Shea Products
1721 W. Hamlin Rd.
Rochester Hills, MI 48309
(313) 852-4940

TASH, Inc.
Unit 1, 91 Station St.
Ajax, Ontario, Canada L1S 3H2
(416) 686-4129

Xerox Imaging Systems
9 Centennial Dr.
Peabody, MA 01960
(508) 977-2000

• Augmentative Comm. Evaluation

Connecticut

CT Ctr. for Augmentative Communication

St Vincent's Special Needs Center
95 Meritt Blvd.
Tumbull, CT 06611
(203) 375-6400

Providing persons of all ages with evaluation/training in augmentative aids/systems to facilitate communication, writing and computer access.

The Case of the Smuggled Car Seats



Now we've heard it all. Our distributor in Canada reports bootleggers have been smuggling our Orthopedic Positioning Car Seats across the border, bypassing the Canadian bilingual labeling laws—and our distributor—and selling them on the "gray market."

We must admit to being a little flattered. We've heard of gray markets in Mercedes cars and exotic cameras. It's nice our product is classed as so desirable that



people will go to such lengths to bootleg it.

Of course, we know the Columbia Car Seat is unique. It's comfortable, good-looking, supportive. Best of all, it has been crash tested for

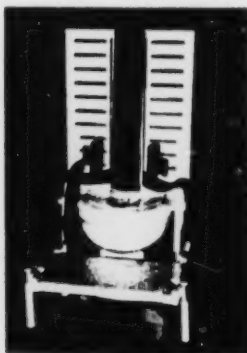
children 20 to 102 lbs., up to 5 feet tall! Made in the U.S., it exceeds Federal safety standards (and Canadian standards, too) and is FAA approved for use in aircraft.

If you're reading this in the U.S., you can get the Columbia Car Seat at your nearest dealer with no hanky-panky. If you're in Canada, be sure to look for the Canadian labeling before you buy.

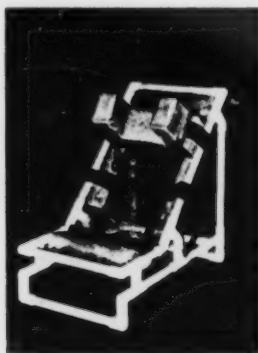
Ask for our FREE full-color catalog of convenient, helpful products

COLUMBIA

continued on page 12



Our Toilet Supports will "grow" right along with your child. Toddlers thru adults can use our Toilet Supports. We have High Back and Low Back Supports. A pommel and a toilet seat insert for small children are also available.



Our custom built Bath Chairs are designed to keep the user securely in place. There are numerous options to make this chair just right for your child. Why choose an off-the-shelf bath chair when we will build a custom chair just for your child?

For a free brochure call or write:

The Adaptive Design Shop

12847 Pt. Pleasant Drive
Fairfax, VA 22033
703-631-1585

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Help us spread the word about *Exceptional Parent* at your next meeting, workshop or seminar. Return this coupon to receive FREE Issue Cards for distribution at your next event.

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_____ (meeting) on ____/____/93.

NAME _____

ADDRESS _____

CITY _____

STATE _____

ZIP _____

Bonus 93

ANNUAL GUIDE TO PRODUCTS & SERVICES

Aug. Comm. Evaluation (cont'd)

Florida

Communication Systems Evaluation Center

434 N. Tampa Avenue
Orlando FL 32805
(407) 849-3504

State-wide services in evaluation, follow up, and training for professionals and families. Services are free of charge, age 3-21.

Minnesota

Gillette Children's Hospital

200 E. University Ave.
St. Paul, MN 55101
(612) 291-2848

Provide med. treatments, therapies and customized equip., such as aug. comm. devices & wheelchairs to children & adolescents w/disabilities

• Bathroom Equipment

AccessAble Environments
43 King St.
Portchester, NY 10573
(800) 285-2525

Adaptations

1758 Empire Central
Dallas, TX 75235
(800) 688-1758

Specializing in door and bath hardware for people with physical limitations.

The Adaptive Design Shop

12847 Pt. Pleasant Dr.
Fairfax, VA 22033
(703) 631-1585

Our toilet supports adjust to fit toddler thru adults. No need to ever buy another. Our bath chairs are custom made to fit your child. see ad page 12

Andermac

2626 Live Oak Hwy.
Yuba City, CA 95991-8810
(800) 824-0214

Arjo-Century

8130 Lehigh Ave.
Morton Grove, IL 60053
(800) 323-1245

BathEase, Inc.

2537 Frisco Dr. #300
Clearwater, FL 34621-3821
(813) 791-6656

Carderock Limited

P.O. Box 4061
Rockville, MD 20850
(202) 342-9390

Columbia Medical Mfg. Corp.

P.O. Box 633
Pacific Palisades, CA 90272
(310) 454-6612
see ads pages 11 & 13

Dynamic Life Products
3215 E. Hearn
Phoenix, AZ 85032
(602) 867-8243

Electric Mobility Corp.
1 Mobility Plaza
Sewell, NJ 08080
(800) 662-4548

Guardian/Sunrise Medical
12800 Wentworth St.
Arleta, CA 91331
(800) 423-8034

Hydra Commode Lift
9833 Whetstone Dr.
Gaithersburg, MD 20879
(301) 990-8810

Little John Enterprises
P.O. Box 844
St. Cloud, MN 56302
(612) 252-5100

Sanco Handicap Aids
P.O. Box 86
Hurley, MS 39555
(601) 588-9916

Sanlex International, Inc.
P.O. Box 14717
Dayton, OH 45413-0717
(513) 297-3011

Shower Power
205 N. Collier Blvd.
Marco Island, FL 33937
(813) 642-7839

Silcraft Corporation
528 Hughes Dr.
Traverse City, MI 49684
(616) 946-4221

Spartan Healthcare Products
P.O. Box 9725
Jackson, MS 39286-9725
(601) 362-1677

Tub Master Corp.
413 Virginia Dr.
Orlando, FL 32803
(407) 898-2881

Tubs, Inc.

7 Monroe St.
Troy, NY 12180
(518) 274-BATH (2284)
Our unique bathtub has a door in the side wall allowing the user to walk or transfer into the tub rather than stepping over the edge

Vogel Enterprises
2105 Berrywood Ln.
Bloomington, IL 61704
(309) 662-4868

**For Exceptional Parent
subscription information, call
(800) 247-8080**

ANNUAL GUIDE TO PRODUCTS & SERVICES

• Bedding

Care Systems, Inc.
87 N. Clinton Ave., Ste. 404
Rochester, NY 14604
(716) 264-1210

Hard Manufacturing
230 Grider St.
Buffalo, NY 14215
(800) USE-HARD

• Catalogs

Accelerated Human
1405 Miramar St.
Valdosta, GA 31601
(912) 247-1747

Achievement Products, Inc.
2045 Niagra Falls Blvd. #1314
Niagra Falls, NY
(716) 298-4700

A/V Health Services, Inc.
P.O. Box 20271
Roanoke, VA 24018
(703) 389-4339 Voice/Fax
A/V Health Services offers a free catalog of instructional, exercise, and motivational video tapes for the physically challenged.

AdaptAbility

Dept. 2292
Colchester, CT 06415
(800) 243-9232 Dept. 2292
Adaptive home products, therapy games and activities, eating aids, writing aids. Free catalog with pediatric section.

American Discount Medical
2850 Jamacha Rd. #147-218
El Cajon, CA 92019
(619) 660-9100

Attainment Company, Inc.
504 Commerce Pkwy.
Verona, WI 53593
(608) 845-7880

Bruce Medical Supply
411 Waverly Oaks Rd.
Waltham, MA 02154
(800) 225-8446

Cambridge Development
214 Third Ave.
Waltham, MA 02154
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continued on page 20

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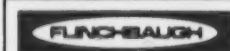
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P.O. Box 89, Dept. 1330
Jackson, MI 49204-0089
(800) 631-7277

Tumble Forms' newest positioner: the Trislander - a 3 in 1 support; supine, prone or standing. Tilts from 15-90°. Adjusts for kids 32-47" tall. Came Rover seat/ stroller combo has a new compact, light base. Easy to move inside and out. Smooth ride too.
see ads pages 41 & back cov.

Jay Medical, Ltd.
P.O. Box 18656
Boulder, CO 80308
(303) 442-5529
see ad page 6

Kaye Products, Inc.
535 Dimmocks Mill Rd.
Hillsborough, NC 27278
(919) 732-5444

Ken McRight Supplies, Inc.
7456 South Oswego
Tulsa, OK 74136
(918) 492-9657

Kid Kart/Kid Care
7175 Sykes Canyon
Bozeman, MT 59715
(406) 388-1080

Life Enhancement Products, Inc.
300 Oak St.
Pembroke, MA 02359
(617) 826-7447

LoveLift
P.O. Box 2158
Holland, MI 49422-2158
(616) 393-8941

Marketing Services
5900 First Ave. S
Seattle, WA 98108
(206) 767-3500

Miller's Special Products
284 E. Market St.
Akron, OH 44308
(216) 376-2500

Motor Development
9340 Buell St.
Downey, CA 90241
(310) 862-6741

continued on page 26

NEW!

THE™ DUET ...A new kind of freedom!

Now you can share an active lifestyle with your friends and family. Enjoy the scenery, the fresh air and the exhilaration of the outdoors.

is a ruggedly built wheelchair/bike, with accessories to custom fit any special seating needs you may have, for children or adults.

1000 physically challenged Duet-owners in 25 countries already participate in outdoor recreational activities.

For information of the location of your nearest dealer, please contact
ROBERT HOENING MOBILITY SYSTEMS, INC.

(303) 220-0983

7348 S. Alton Way • Suite L
Englewood, CO 80112

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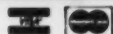
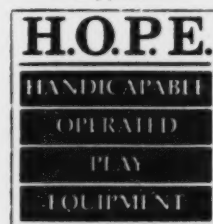
for children with a disability

STANDARD OPTIONS

- digital electronics controls
- multiple switch options
- adjustable speed controls
- seating options
- battery operated
- battery charger included



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N E W

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- Proportional Joystick Steering
- RF Control w/Emergency ON/OFF and Proportional Steering
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1-800-950-5185

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830 48th Street
Grand Forks, ND 58201
Phone: (701) 772-5185
Fax: (701) 772-5284

Seating/Positioning (cont'd)

Omrion Healthcare, Inc.
300 Lakeview Pkwy
Vernon Hills, IL 60061
(708) 680-6200

Ortho-Kinetics Inc.

P.O. Box 1647
Waukesha, WI 53187
(800) 824-1068

Introducing an innovative head restraint called Hans (head and neck support). This revolutionary product is adjustable for length and curvature requirements, allows complete freedom of movement and has no chin strap for little visual impact. *see ad page 27*

ORTHO FAB, Inc.
2160 De Celles
Quebec, QC G2C 1X8
(418) 847-5225

Orthotic Prosthetic Center
8330 Professional Hill Dr.
Fairfax, VA 22031
(703) 698-5007

Otto Bock Orthopedic
3000 Xenium Ln. N
Minneapolis, MN 55441
(800) 328-4058

Pin Dot Products
6001 Gross Point Rd.
Niles, IL 60648-4027
(312) 774-1700

PostureMate, Inc.
139 Burke Ln.
Kneeland, CA 95549
(707) 445-4841

Prospect Designs
11 Prospect St.
New Hartford, CT 06057
(203) 379-7858

Pyramid Rehabilitation
4993 Southern
Memphis, TN 38117
(800) 962-7615

Rancho Therapy Products
22865 Savi Ranch Pkwy., Ste. E
Yorba City, CA 92686
(714) 283-3925

REM Productions

P.O. Box 1429
Old Chelsea Station
New York, NY 10011
Positioning for activity is a 30-min. videotape demonstrates techniques and equipment for positioning. For parents, teachers, and therapists.

Rifton Equipment
Rte. 213
Rifton, NY 12471
(914) 658-3141

ROHO, Inc.

100 Florida Ave.
Belleville, IL 62221-9990
(800) 851-3449
Protect and properly position your child with a pediatric seating system from ROHO, Inc. ROHO Pediatric Seating Systems adjust to your growing child.

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P.O. Box 1739
Matthews, NC 28106
(800) 336-7684
Pediatric postural seating and mobility systems (some suitable for bus tie-downs). Automotive seats, standing devices, and adaptive strollers.

Special Health Systems
90 Englehard Dr.
Aurora, Ontario L4G 3V2
(416) 841-1032

Therapeutic Design, Inc.
1850 Lee Rd., Ste. 325
Winter Park, FL 32789
(407) 740-7874

Toronto Orthopedic
385 Keele St.
Toronto, ON M6P 2K9
(416) 766-6800

• Standing Equipment

ALTime Medical, Inc.
913 S. Washington St.
Redwood Falls, MN 56283
(507) 637-3331

The Merry Walker
1357 Northmoor Ct.
Northbrook, IL 60062
(800) 827-8318

Prime Engineering
4838 W. Jacquelyn #105
Fresno, CA 93722
(209) 276-0991

Quickie Designs
2842 Business Park
Fresno, CA 93727-1328
(800) 456-8168
see ad page 5

Stand Aid of Iowa, Inc.

P.O. Box 386
Sheldon, IA 51201
(800) 831-8580
Roll-Aid allows wheelchair users to go from manual to power in seconds, with no assistance. The Roll-Aid attachment system locks on to your chair and you're ready to drive away under full power. The Roll-Aid allows users to continue to fold their chair for transport.

Rand Scot, Incorporated
401 Linden Center Dr.
Fort Collins, CO 80524
(303) 484-7967

Taylor Made
10 W. Ninth St.
Gloversville, NY 12078
(518) 773-9214

• Toys and Hobbies

Center for Applied Psychology
441 N. Fifth St.
Philadelphia, PA 19123
(215) 668-9881

Flavia Club
925 de la Vina St. #300
Santa Barbara, CA 93101
(805) 564-6909

Special Needs Project

1482 E. Valley Rd. #A-121
Santa Barbara, CA 93108-1200
(800) 333-6867
Hod Gray's FREE Special Needs Project catalog is a unique source of BOOKS for children and adults. Information about parenting a child with a disability, disability awareness, assistive technology, ADA rights and more ... there's no one like SNP!

TFH Achievement & Special Needs
4449 Gibsonsia Rd.
Gibsonsia, PA 15044
(412) 444-6400

The Able Child
P.O. Box 250
Bohemia, NY 11716
(516) 563-7176

The Capable Child
8 Herkimer Ave.
Hewlett, NY 11557
(516) 295-3117

The Silver Thorn Group
Box 8
Brinklow, MD 20862
(301) 774-4966

Therapeutic Toys, Inc.
34 N. Moodus
Moodus, CT 06469
(203) 873-2003

Toys for Special Children
385 S. Warburton Ave.
Hastings-on-Hudson, NY 10706
(914) 478-0960

Woodstock Percussion, Inc.
Rt. 1, Box 381 A
West Hurley, NY 12491
(914) 331-2450

• Van Conversion

B & R Mobility Services

914 E. Skagway Avenue
Tampa, FL 33604
(813) 933-5452
We sell and service adaptive equipment in the aid of transportation for the physically impaired. We can provide anything from hand controls for a car to a complete van conversion for the disabled driver and passenger. For more information, give us a call!

Lift Aids, Inc.

2381 Pecan Ct.
Ft. Worth, TX 76117
(817) 834-3881/429-7141 (Metro)
Installer of special adaptive equipment and custom conversions focusing on the special needs of each individual family.

Mobility Concepts, Inc.

99 SW 10th Avenue Bay D
Hallandale, FL 33009
(305) 456-6096
Complete vehicle modifications. NMEDA cars, mini-vans, full size vans. Feature prod: Braun, Crow-River, Buno, IMS, MPD, Ricon, Drive-Master, MPS, EZ-Lock, touch pad controls. Facility is government certified, factory authorized - experience and consumer friendly

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Adaptive Driving Systems, Inc.
21050 Superior St.
Chatsworth, CA 91311
(818) 998-1026

Ahnafeld Corporation
3219 W. Washington St.
Indianapolis, IN 46222-4001
(317) 636-8061

Arcola Vehicles
51 Kero Rd.
Carlstadt, NJ 07072
(201) 507-8500

Associated Leasing
600 121st Street
Burnsville, MN 55337
(612) 890-7851

The Braun Corporation

1014 S. Monticello Street
Winamac, IN 46996
(800) 843-5438
EnterVan, a lowered floor Chrysler minivan with a folding ramp. The EnterVan is the perfect choice for growing families.

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Care Concepts International
353 W. Osborne Rd.
Phoenix, AZ 85017
(602) 274-1432

Chrysler Corporation (P-Cap)
P.O. Box 159
Detroit, MI 48288
(800) 255-9877
see ad page 4

Complete Mobility Systems
1901 Oakcrest Ave. #1
Roseville, MN 55113
(612) 635-0655

Contact Technologies, Inc.
11600 Western Ave.
Stanton, CA 90680
(714) 898-7838

Drive Master Corp.
9 Speilman Rd.
Fairfield, NJ 07004-3403
(201) 808-9709

Electro Van Lift, Inc.
1901 Oakcrest Ave. #1
Roseville, MN 55113
(612) 635-0655

Electronic Mobility Controls
2001 Wooddale Blvd.
Baton Rouge, LA
(504) 926-2403

Ford Motor Co.
P.O. Box 94
Bloomfield Hills, MI 48013
(313) 540-6911
see ad inside front cover

Freedom Motors
3111 Woodchester Dr.
Mississauga Ontario L5L 1J2
(800) 561-9600

General Motors Mobility Program
3044 W. Grand Blvd.
Detroit, MI 48202
(800) 323-9935

Gresham Driving Aids, Inc.
P.O. Box 405
Wixom, MI 48096
(800) 521-8930

Independent Mobility Systems
4100 Piedras
Farmington, NM 87401
(505) 326-4538

Kroepke Kontrols, Inc.
104 Hawkins St.
City Island, NY 10464
(718) 885-1100

Med Net, Inc.
P.O. Box 948
Battle Creek, MI
(616) 962-3800

Mobile-Tech Corporation
HABIT
Hutchinson, KS 67505
(316) 663-4441

Mobility Concepts, Inc.
99 SW 10th Avenue Bay D
Hallandale, FL 33009
(305) 456-6096

Mobility Technology
P.O. Box 1493
Battle Creek, MI 49016
(616) 965-2291
see ad page 23

Monmouth Custom Vans
5105 Route 33 & 34
Farmingdale, NJ 07727
(908) 938-4050

National Mobility Corp.
28936 Phillips St.
Elkhart, IN 46514
(219) 262-8349

Q'Straint

4248 Ridge Lea Rd.
Buffalo, NY 14226
(716) 831-9959

A universal wheel chair and occupant restraint system. Every component is designed, engineered and tested to work together to prevent passenger injury in a collision. If you are responsible for safety, Q'Straint puts that safety as the single most important priority.

Specialty Transport
2800 N. Main Ave.
Newton, NC 28658
(800) 582-5546

Vantage Mini Vans
2441 E. Chambers Rd.
Phoenix, AZ 85040
(602) 243-2700
see ad inside back cover

Volkswagen
3800 Hamlin Rd.
Auburn Hills, MI 48326
(313) 340-5000

Wheeler's
6614 W. Sweetwater Ave.
Glendale, AZ 85304
(602) 878-3540

• Vision Aids

American Foundation for the Blind
15 W. 16th St.
New York, NY 10011
(212) 620-2075

**For Exceptional Parent
subscription information, call
(800) 247-8080**

continued on page 28

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	July/Aug 1992	"Mini" Comm. Boards; Incontinence; A Flag-Flying 4th; Augmentative Comm.	
	March 1992	3rd Annual Mobility Guide: Wheelchair Maintenance; Children & the ADA; Van Lifts;	
	Nov/Dec 1991	9th Annual Computer Technology Issue; Parenting Your Child Without Disabilities.	
	Oct/Nov 1991	Is Your Child Being Humiliated? Car Seat Safety; Tips for Parents; 800# Directory.	
	September 1991	19th Annual Education Issue; School Bus Safety; Schools, Ins. & Your Family's Financial Security.	
	July/Aug 1991	Corporate Award — McDonald's; One Mother's Quest for Normalcy; Bathroom Accessibility.	
	June 1991	Summer Program Winners; Mainstreaming; Social Security Can Help; Seating & Positioning.	
	Nov/Dec 1990	8th Annual Technology Issue; Annual Income Tax Guide; 1990 Best Tech. & Everyday Life Awards.	
	October 1990	Parent to Parent National Survey; Adaptable Playgrounds; Finding the Right Software.	
	July/Aug 1990	Teaching About Sexuality; Preparing for Surgery; Aquatic Activities.	
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Bonus 93

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P.O. Box 5181
Salem, OR 97304
(503) 581-4224

Lifeprints, a career magazine for blind youth & adults, and Dialogue, an entertaining and educational magazine for blind adults.

Raised Dot Computing, Inc.
408 S. Baldwin St.
Madison, WI 53703
(608) 257-9595

• Wheelchairs - Manual

Activeaid, Inc.
P.O. Box 359
Redwood Falls, MN 56283
(507) 644-2951

Advanced Mobility Systems
621 Justus Dr.
Kingston, Ontario K7M 4H5
(613) 384-7460

Allied Medical Supply
P.O. Box 5122
Richmond, VA 23220
(800) 446-3702

California Cruisers
21742 Marilla St.
Chatsworth, CA
(818) 882-6988

Canadian Wheelchair
1360 Blundell Rd.
Mississauga, Ontario L4Y 1M5
(416) 275-3960

Check✓Marc (Repair Ctrs.)

3223 South Loop 289, Ste. 600
Lubbock, TX 79423
(800) 477-MARC (6272)
(806) 793-0106

A national network of authorized repair ctrs. certified in the repair of manual and power wheelchairs. Check✓Marc repair centers offer efficient reliable, guaranteed repair services, extended warranties and customer service second to none.

Colours 'N Motion
1591 S. Sinclair St., Ste. A
Anaheim, CA 92806
(714) 978-1440

Convaid Products, Inc.

P.O. Box 2458
Rancho Palos Verdes, CA 90274
(310) 539-6814

Compact-folding, lightweight positioning buggies for all ages, three sizes, three colors, over 20 positioning features. Five year warranty
see ad page 43

Eagle Sportschairs
2351 Parkwood Rd.
Snellville, GA 30278
(404) 972-0763

ENDURO/Wheel Ring, Inc.

199 Forest St.
Manchester, CT 06040
(203) 647-8596

ENDURO offers a complete line of pediatric & adult wheelchairs with optional seating and accessories. We specialize in pediatric rehab mkt.

Equipnet, Inc.
200 E. Del Mar Blvd.
Pasadena, CA 91105
(800) 366-0232

Everest & Jennings
1100 Corporate Sq.
St. Louis, MO 63132
(314) 995-7058
see ad page 1

Falcon Rehabilitation Products
4404 E. 60th Ave.
Commerce City, CO 80022
(303) 287-6808

Forward Motion
1625 Olympic Blvd.
Santa Monica, CA 90404

Freedom Designs, Inc.
2241 Madera Rd.
Simi Valley, CA 93065
(805) 582-0077

Gendron, Inc.
P.O. Box 197
Archbold, OH 43502
(800) 537-2521

Halls Wheels
Box 784
Cambridge, MA 02143
(617) 628-7855

Invacare
Box 4028
Elyria, OH 44036
(800) 424-4214

Iron Horse Productions, Inc.
2624 Conner St.
Port Huron, MI 48060
(800) 426-0354

Jaken Medical
2310 E. Orangethorpe Ave.
Anaheim, CA 92806
(800) 689-4499

Kushall of America
753 Calle Plano
Camarillo, CA 93012
(805) 484-3595

LDC Corporations of America
780-B2 Primos Ave.
Folcroft, PA 19032
(800) 782-6324

Mulholland Positioning
P.O. Box 391
Santa Paula, CA 93060
(805) 525-7165

Quickie Designs
2842 Business Park
Fresno, CA 93727-1328
(800) 456-8168
see ad page 5

Robert's Wheelchairs, Inc.
121 W. Hazel St.
Inglewood, CA 90302
(310) 674-1194

Scott Designs
2169 Las Positas Ct., Ste. C
Livermore, CA 94550
(510) 294-1700

Skyway Products
4451 Caterpillar Rd.
Redding, CA 96003
(916) 243-5151

Suburban Ostomy
75 October Hill Rd.
Holliston, MA 01746
(508) 429-1000

Top End Wheelchair Sports
4501 63 Circle N
Pinellas Park, FL 34665
(813) 522-8677

Wheelin Designs
18 Don Crest Rd., Unit 4
Toronto, Ontario M4K 1P8
(416) 469-3999

Wheelsport International
4331 W. Santa Ana
Fresno, CA 93722
(209) 276-3271

XL Manufacturing Co., Inc.
4950 Cohasset Rd.
Chico, CA 95926
(916) 891-3535

• Wheelchairs - Power

Amigo Mobility International
6693 Dixie Highway
Bridgeport, MI 48722-0402
(800) 248-9130

Check✓Marc (Repair Ctrs.)

3223 South Loop 289, Ste. 600
Lubbock, TX 79423
(800) 477-MARC (6272)
(806) 793-0106

A national network of authorized repair ctrs. certified in the repair of manual and power wheelchairs. Check✓Marc repair centers offer efficient reliable, guaranteed repair services, extended warranties and customer service second to none.

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Chatsworth, CA 91311
(818) 709-4534

Port. pwr/man wchrs. in custom sizes for kids and adults. The D90 Power Conversion System converts most manual wheelchairs to power.

Everest & Jennings
1100 Corporate Square
St. Louis, MO 63132
(314) 995-7058
see ad page 1

Excel Mobility Products, Inc.
636 Constitution Ave.
Washington, D.C. 20002
(202) 544-0323

Fortress
P.O. Box 489
Clovis, CA 93613-0489
(209) 323-0292

Invacare
Box 4028
Elyria, OH 44036
(800) 424-4214

LEVO USA
21050 Superior St.
Chatsworth, CA 91311
(818) 882-6944

Permobil, Inc.
6-B Gill St.
Woburn, MA 01801
(800) 736-0925

Quest Technology
766 Palomar Ave.
Sunnyvale, CA 94086
(408) 739-3550

Quickie Designs
2842 Business Park Ave.
Fresno, CA 93727-1328
(800) 456-8168

Wheeling Free, Inc.

6032 Sierra Siena Rd.
Irvine, CA 92715
(800) 484-9793, ext. 1600

The Maxi features three-wheel rear castor design for stability, quick turning in a small space and easy rolling. Tilt seat. With adjustment 11" to 22". Camber by hand in seconds. Capacity: 250+ lbs. Weight: 25 lbs.

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Eugene, OR 97404
(503) 688-3072

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"*Exceptional Parent* ... is the finest publication of its kind ... must reading for all those with a handicapped child. It could change their lives.

Ann Landers

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I highly recommend *Exceptional Parent* magazine to all parents of children with disabilities."

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*Clinical Professor of Pediatrics
Harvard Medical School*

*Author of Doctor and Child, On Becoming A Family,
What Every Baby Knows, Infants and Mothers,
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featuring

When Your Child Is Seriously Injured:

The Emotional Impact on Families by Marilyn Lash.
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And JUST PUBLISHED!!

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by Marilyn Lash. A 72-page booklet that helps families
prepare for their child's entry or return to school
after a serious injury (see page 48 for excerpt).

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When Your Child Is Seriously Injured

- ☐ One copy \$4.50 ☐ 10 copies \$25.50 ☐ 20 copies \$42
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Address

City

State

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Mail to: **Exceptional Parent**, 1170 Commonwealth Ave., Boston, MA 02134-4646

**"Jeff can now hold
his head high.
Thanks to HANS®!"**

Now with the innovative HANS®, Head and Neck Support, disabled people who lack neck and upper torso strength are able to hold their heads up high with ease.

Without use of bulky supports and excessive restraints, HANS® helps the wearer's head to move with the person's torso, allowing comfortable head positioning. HANS® also is lightweight and easy to adjust for a custom fit so everyday life can be more enjoyable. Crash testing has even demonstrated that HANS® can be worn in vehicles with proper seating restraints.

With the advanced design of the new HANS® making it comfortable and compatible with other mobility and positioning products, people with disabilities will enjoy a new outlook on life.

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Ortho-Kinetics, Inc.



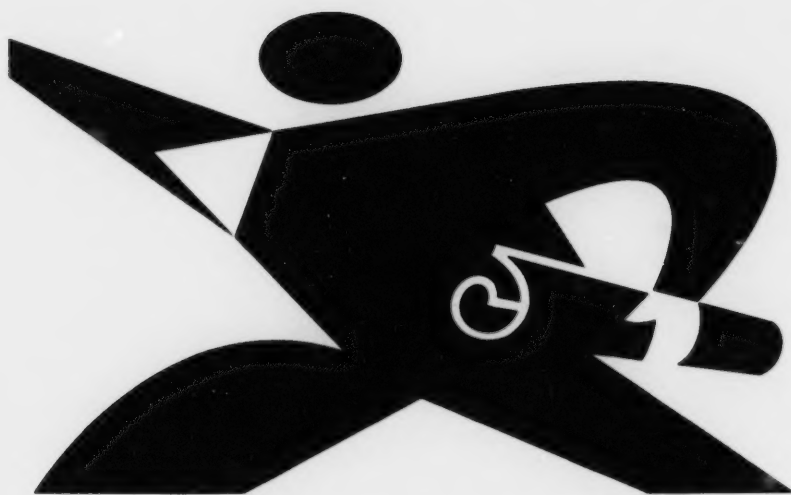
For more information, call our
Customer Service Hotline at 1-800-824-1068



Ortho-Kinetics
Box 1647, Waukesha, WI 53186

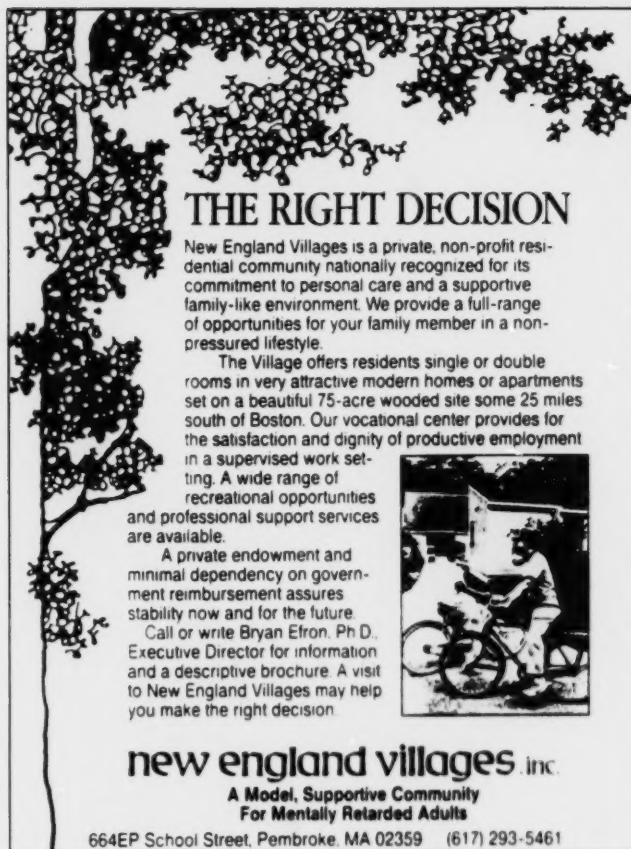
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On January 5, 1993 Apple Computer, Inc. began a revolution. Coup de Tech. It's a welcome, of sorts, to the 21st Century. And a kick in the pants to business as usual. Since that day, individuals from around the world have come together to change what it means for a child or an adult to experience a disability.



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20525 Mariani Avenue, M/S 2-SE Cupertino, California 95014 USA



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Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

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- Speech and Language Therapy
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Devereux Arizona

6436 East Sweetwater Avenue
Scottsdale, AZ 85254
(602) 998-2920

Residential and day programs for children and adolescents with emotional disorders and/or learning disabilities.

Hacienda de los Angeles, Inc.

1402 East Mountain Ave.
Phoenix, AZ 85040
(602) 243-4231

State-of-the-art care for medically fragile children and adults. A federally certified-intermediate care facility for MR, advanced medical care consisting of 24-hr. skilled nursing, respiratory care, in-house PT and OT.

California

Devereux Santa Barbara

P.O. Box 1079
Santa Barbara, CA 93102
(805) 968-2525/(800) 359-7979

Res., day, and comm. progs. for children & adults who have a wide range of developmental disorders and/or emotional disorders.

Frostig School

971 N. Altadena Drive
Pasadena, CA 91107
(818) 791-1255

Private nonprofit school for learning disabled children without serious emotional problems. The school provides an interdisciplinary education for children 6 through 18 years of age. Nurturing, whole child oriented, with strong enrichment opportunities.

Connecticut

Devereux Glenholme

81 Sabbathday Lane
Washington, CT 06793
(203) 868-7377

Residential treatment ctr. for children and adolescents, 5-15, with emotional disorders, incl. ADD and learning disabilities.

Riverbrook

108 Glen Road
Stockbridge, MA 01230
(413) 298-4926

Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

Delaware

Devereux Wrangle Hill

3560 Wrangle Hill Road
Bear, DE 19701
(302) 834-8416

A res. prog. for children with emotional disorders (placed in care by the Del. Div of Child Mental Health).

District of Columbia

Devereux Children's Center

3050 R Street, NW
Washington, DC 20007
(202) 282-1200

Res. treatment svcs. for children with emotional dis., ages 6-12, who have been referred by the Dept. of Human Svcs., Washington, D.C.

Florida

Devereux Florida Treatment Network

Hospital, res. community and day prog. for children and adolescents with emotional, conduct and developmental disorders. Special services: therapeutic foster care, outpatient/in-home services. Available.

Devereux Hospital and Children's Center

8000 Devereux Drive
Melbourne, FL 32940
(407) 242-9100

Devereux Orlando Center

6131 Christian Way
Orlando, FL 32808
(407) 296-5300

The Duvall Home

3395 Grand Ave., P.O. Box 36
Glenwood, FL 32722
(800) 358-0450

A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and nonambulatory mentally handicapped of all ages. 24-hour nursing care. Lovely 24-acre rural campus. Recreational and training activities. Respite care available.

Georgia

Agape Village

Dr. Glenda B. Wallace
3711 Agape Village Rd.
Macon, GA 31310-4057
(912) 471-3700

Provides home living, social, work training plus paying jobs in 50-acre village setting. Individual program goal, semi-independent living for \$1125/month. Co-ed, ages 17 and over. Residential community for MR/intellectually disabled adults.

continued on page 34

Working together for a better future!



At Devereux, the concept of working together is emphasized and encouraged.

In residential, day, and community-based treatment centers nationwide, Devereux provides comprehensive services to individuals of all ages who have:

- Emotional disturbances
- Developmental disabilities
- Mental retardation
- Dual diagnoses
- Autism
- Post-head trauma

Devereux services:

- A wide range of therapeutic, educational, and vocational

programs tailored to the specific needs of the individual

- Individual, group, and family therapies

Devereux programs:

- Residential centers
- Specialized psychiatric hospitals/intensive residential treatment centers
- Community-based living

Devereux locations:

Arizona, California, Connecticut, Delaware, Florida, Georgia, Maryland, Massachusetts, New Jersey, New York, Pennsylvania, Texas.

Contact: National Referral Services
1-800-345-1292, X3045 or
215/964-3045
FAX: 215/971-4600



SCHOOLS, CAMPS & RESIDENCES DIRECTORY

Georgia (cont'd)

Devereux Georgia

1291 Stanley Road, N.W.
Kennesaw, GA 30144
(404) 427-0147/(800) 342-3357

Psychiatric hospital/intensive residential treatment program for adolescents who have emotional, behavioral and/or learning disorders.

Illinois

The Hope School

50 Hazel Lane, P.O. Box 5810
Springfield, IL 62705
(217) 786-3350

Private, licensed, not-for-profit residential school for children with multiple disabilities. 25 acres near Lake Springfield in central Illinois.

St. Coletta School

W4955 Highway 18
Jefferson, WI 53549
(414) 674-4330

Year-round res. prog. in academic instruction and prevocational training for MR/DD. Adult res. facility w/ work opportunities for aging MR/DD.

Kansas

Institut[®] of Logopedics

2400 Jardine Drive
Wichita, KS 67219
(800) 835-1043

Residential school for children 5-21 with multiple disabilities. Intensive speech, physical, and occupational therapies available. Evaluation options and treatment planning available. Emphasis on transition to home environment. Summer and full year.

Kentucky

The dePaul School

1925 Duker Avenue
Louisville, KY 40205
(502) 459-6131

For children with a perceptual motor disability, dyslexia. Private non-profit school with full time program, Saturday, summer boarding prog.

Maryland

Devereux Resources for Special Children

9515 Reisterstown Rd.
Owings Mills, MD 21117
(410) 363-3100

Info. and support resource to clients/families - inc. eval./ admissions, prog. planning and post-discharge, family counseling, ed. training.

Massachusetts

Berkshire Children's Community

249 N. Plain Rd.
Housatonic, MA 01236
(413) 528-2523

For children who are severely retarded, multiply disabled. Private, nonprofit, residential school located in the Berkshires.
see ad page 35

Cardinal Cushing School and Training Center

400 Washington Street
Hanover, MA 02333
(617) 826-5371

Provides academic, residential and vocational prog. for all levels of developmentally delayed students to help them lead fulfilling, productive lives. Program includes Prader-Willi Syndrome and international students. Ages 6-22.

Cotting School

453 Concord Avenue
Lexington, MA 02173
(617) 862-7323

Day school for boys and girls with physical and learning challenges, communication deficits, and students who are medically involved.
see ad page 37

Crystal Springs School

38 Narrows Rd., Box 372
Assonet, MA 02702
(508) 644-3101, Ext. 328

Established in 1953, Crystal Springs offers licensed homelike residences; an approved private school; full rehab program; and 24-hour licensed nursing coverage designed to meet the needs of medically fragile, multihandicapped children and young adults, birth-22 years.

Devereux Massachusetts

60 Miles Rd., P.O. Box 197
Rutland, MA 01543-0197
(508) 886-4746

A residential program for children, adolescents and young adults who have emotional disorders and developmental and learning disabilities.

Franciscan Children's Hospital & Rehab. Ctr.

30 Warren Street
Boston, MA 02135-3680
(617) 254-3800

100-bed, nonprofit facility offering rehab. and acute inpatient care, ambulatory services and special education to children ages 0-21 with disabilities. A major teaching affiliate of Boston University School of Medicine.

League School of Boston, Inc.

225 Nevada St.
Newtonville, MA 02160
(617) 964-3260

Offers 12-month day educational prog. specialized community residences, early intervention home training, community-based supportive employment & vocational training, after-school recreational prog. and friendship farms.

The Learning Center

411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

Private, community-based 12 month, day/residential school for individuals 8-22 years with MR and other special needs.

The New England Center for Autism

33 Turnpike Road
Southboro, MA 01772
(508) 481-1015

Day/residential school for children with develop. disabilities, behavior disorders age 3-22. Integrated preschool, inclusion svcs., staff intensive prog., functional activity based curr., supported employment in modern school and group homes.

New England Pediatric Care

78 Boston Rd.
No. Billerica, MA 01862
(508) 667-5123

Integrated rehabilitation, skilled nursing and educational service for disabled, medically complex children from birth to 22. Extended admissions as well as short-term stays facilitating early hospital discharge and transition to home/community.

New England Villages Inc.

664 EP School Street
Pembroke, MA 02359
(617) 293-5461

Private residential community for adults with developmental disabilities. Vocational, recreational programs.
see ad page 32

Project School Care Children's Hospital

300 Longwood Avenue
Boston, MA 02115
(617) 735-6714

Training, publications and consultations on children assisted by medical technology in educational settings in Mass. and elsewhere.

Riverbrook

108 Glen Road
Stockbridge, MA 01230
(413) 298-4926

Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

Riverview School

551 Route 6A, East Sandwich
Cape Cod, MA 02537
(508) 888-0489

For high school students (12-19) who are learning disabled but also marginally impaired intellectually. Located on Cape Cod, Riverview offers a modified curriculum which provides a high school diploma. Post graduate programs are also available.

Minnesota

Camp Buckskin

3811 W. Broadway
Attn: EPM
Minneapolis, MN 55422

Specializes in children with LD, ADHD or EMH ages 6-18. Program actively seeks to develop self-confidence, improve social skills and enhance self-concept. Individualized attention and encouragement promote success in academics and traditional camp activities!

New Hampshire

Crotched Mountain

Verney Drive
Greenfield, NH 03047
(603) 547-3311

A prep. school and therapy ctr. for children with: head injury, CP, spina bifida, MR, developmental, behavioral, emotional and seizure disorders. Modern residential group homes. Transitional residential apartments. Licensed nursing facility. Day students.

Franciscan Children's Hospital & Rehab. Ctr.

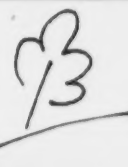
30 Warren Street
Boston, MA 02135-3680
(617) 254-3800

100-bed, nonprofit facility offering rehab. and acute inpatient care, ambulatory services and special education to children ages 0-21 with disabilities. A major teaching affiliate of Boston University School of Medicine.

continued on page 36



For Severely Retarded, Multihandicapped Children BERKSHIRE CHILDREN'S COMMUNITY



PRIVATE, NON-PROFIT RESIDENTIAL SCHOOL

- STATE-OF-THE-ART CAMPUS IN BERKSHIRES
INDOOR THERAPY POOL, ASSISTIVE ARCHITECTURE
- INTENSIVE THERAPIES
SPEECH, PHYSICAL, AND PRE-VOCATIONAL
- INNOVATIVE LEARNING CENTER
UNIQUE CURRICULUM, 12 MONTH SCHOOL
- ADVANCED MEDICAL CARE
AROUND-THE-CLOCK, LEADING SPECIALISTS,
AFFILIATION WITH MAJOR MEDICAL CENTERS
- PARENT ASSOCIATION AND OPEN DOOR VISITING
- NURTURING AND HOME-LIKE



Contact

GAIL CHARPENTIER, DIRECTOR
BERKSHIRE CHILDREN'S COMMUNITY
249 NORTH PLAIN ROAD
HOUSATONIC, MA 01236

413-528-2523

EXCEPTIONAL PARENT PRESS

What If You Couldn't ...? A Program about Disabilities



This multimedia program for elementary school (grades 2-5) presents children with a non-threatening picture of what it might be like to have a disability. This sensitizing is a must for every school involved in mainstreaming. There are seven major areas of study (kits): opening unit, learning disabilities, visual impairment, emotional problems, hearing impairments, orthopedic handicaps and mental retardation. Each of the units gives information first, then simulation experiences and problem-solving exercises. An easy-to-use teachers' guide is included.

MASTER KIT

The Master kit includes one of each kit with guide, packed in a foot-locker size, display/storage/transport case.
\$420.00

EVALUATION PACKAGE

The Evaluation package contains one of each of the 7 guides plus all materials for teaching the opening unit, *Some Ways the Same, Some Ways Different*.
\$56.00

MAIL TO:

EXCEPTIONAL PARENT PRESS
1170 Commonwealth Ave., Boston, Mass. 02134-4646

▲ ▲ ▲ Order Form ▲ ▲ ▲

Name _____
Address _____
City _____
State _____ ZIP _____
Telephone _____

I have enclosed my check payable to
Exceptional Parent Press or charge to my:

☐ Mastercard ☐ VISA
Account Number (All Digits)

Expiration Date _____

Signature _____

QTY	TITLE	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES

U.S. — \$3.50 for 1 item,
75¢ for each additional item.
Foreign — \$6.50 for 1 item,
75¢ for each additional item

Sub-Total

MIA Residents
5% Sales Tax

Shipping

TOTAL

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery.
No overseas returns.

Bonus 93

SCHOOLS, CAMPS & RESIDENCES DIRECTORY

New Jersey

Devereux Center for Autism
186 Roadstown Rd.
Bridgeton, NJ 08302
(609) 455-7200

A residential program for individuals, 8 to 22, who have mild to severe mental retardation.

Devereux Deerhaven
230 Pottersville Rd., P.O. Box 520
Chester, NJ 07930
(908) 879-4166

Residential and day programs for females, 10 to 21, who have emotional and behavioral disorders and learning disabilities.

New York

Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

A co-ed res. camp for learning disabled, ADD, neurologically impaired and mild-moderate MR located in the Catskill Mts. of NY state.

Cobb Memorial School
P.O. Box 503
Altamont, NY 12009
For children who are severely/profoundly mentally retarded.
Private, nonprofit, res./day school located in the Heldeberg Mtns.

Devereux New York
Route 9, P.O. Box 40
Red Hook, NY 12571
(914) 758-1899
A residential prog. for individ., 8 - 21, who have develop. disabilities, emotional dis., neurological impairments and/or Prader-Willi syndrome.

Lochland Schools, Inc.
1065 Lochland Road
Geneva, NY 14456
(315) 789-6055
Residential facility for men and women 18 and older who are ambulatory with severe to moderate MR. Private, not-for-profit.

Pathfinder Village
Box 32-A
Edmeston, NY 13335
(607) 965-8377
Opportunities abound in this colonial style village that provides quality life experience for children and adults with Down syndrome.

Riverbrook
108 Glen Road
Stockbridge, MA 01230
(413) 289-4926
Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

North Dakota

Anne Carlsen School
301 Seventh Avenue, NW
Jamestown, ND 58401
(701) 252-3850
Here young people with disabilities can achieve their highest potential. Many programs for intensive evaluation and intervention.

Pennsylvania

Camphill Special Schools
R.D. 1, Box 240
Glenmoore, PA 19343
(215) 469-9236
For children with mental handicaps, familystyle living in rural setting with educ./therapeutic prog. Day/residential, 10 mo. & summer camp.

Devereux Brandywine
Devereux Road
Glenmoore, PA 19343
(215) 942-5968
Residential/day prog. for males, 6 to 21, who have emotional ADD and conduct disorders. Special services for hearing impaired.

Devereux Day School
Leopard Road
Berwyn, PA 19312
(215) 296-6843
Day program for children & adolescents who have social and emotional disorders and/or brain injuries.

Devereux French Center
119 Old Lancaster Rd.
Devon, PA 19333
(215) 964-3269
Res. prog. for adolescents and adults with social/emotional dis., neurological impairments, traumatic head injuries and dual diagnoses.

Devereux Health Services/Comm. Prog. Ctr.
600 Boot Rd.
Downingtown, PA 19335
(215) 873-4945
Res. prog. (incl. group homes) for adults with develop. disabilities & dual diagnoses. Special svcs. adult day placement & respite care.

Devereux Kenner Center
390 E. Boot Rd.
West Chester, PA 19350
(215) 431-8174
Residential programs for children, adolescents and young adults who have MR, developmental disabilities and emotional disorders.

Devereux Mapleton Center
655 Sugartown Rd., Box 297
Malvern, PA 19355-0297
(215) 296-6970 / (800) 433-1184
Residential and in-patient prog. for children, adolescents and young adults with emotional disorders, LD and neurological impairments.

Devereux Pocono Center
R.D. #1, Box 27A
Newfoundland, PA 18445
(717) 676-3237
Residential and day care programs for adults who have emotional disorders, developmental disabilities and mental retardation.

Erie Infants and Youth Home, Inc.
226 East 27th Street
Erie, PA 16504
(814) 454-1534
Community-based residential prog. serving children and young adults with developmental disabilities. 24 hours a day skilled nursing and direct care services, P.T., O.T., speech, recreation-camp, nutrition, behavior management.

H.M.S. School for Children with CP
4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566
Residential/day school prog. for children 2-21 who are severely physically disabled by CP. Integrated therapies. Assistive tech. see ad page 32

Martha Lloyd Community Services
190 W. Main Street
Troy, PA 16947-1199
(717) 297-2185
A private residential program for ambulatory mentally retarded women, ages 15 and older. Emphasis on vocational and community life skills training. Homelike community residence in northcentral Pennsylvania.

Rock Creek Farm
RR #1, Box 54
Thompson, PA 18465
(717) 756-2706
Private, therapeutic summer camp for children with difficulties in social adjustment as a result of LD, NI, ADD, SI, VI, etc. Ages 6-16.

Royer-Greaves School for Blind
118 S. Valley Rd., P.O. Box 1007
Paoli, PA 19301-0913
(215) 644-1818
Private nonprofit residential school serving blind, multi-handicapped children and adults in home-like atmosphere.

**To advertise in
Exceptional Parent's
Schools, Camps & Residences
Guide, call Melissa Fowler at
(800) 852-2884**

Rhode Island

Behavior Research Institute
240 Laban Street
Providence, RI 02909
(800) 231-5405
Drug-free behavioral residential prog. for autistic/MR. No rejections or expulsions. Success with the most difficult cases. 3 to adult.

Hope Academy
240 Laban Street
Providence, RI 02909
(800) 231-5405
Behavioral res. school for hard-to-place adolescents (assaultive, fire setting, sexual acting out, drug problems, suicidal, etc.) Drug-free.

Riverbrook
108 Glen Road
Stockbridge, MA 01230
(413) 298-4926
Res. facility for 22 moderately mentally handicapped women, program emphasizes self care, social, rec. & voc. skills. No upper age limit.

Tennessee

Devereux Genesis Learning Centers
430 B Allied Dr.
Nashville, TN 37211
(615) 832-4222
Day school and treatment prog. for adolescents and young adults who have emotional disorders, mental retardation & learning disabilities.

Texas

Devereux Hospital and Neurobehavioral Institute
1150 Devereux Dr.
League City, TX 77573
(713) 335-1000
Acute care hospital, small living units, school for ind. with severe emotional and/or conduct dis., pervasive dev. dis., brain injuries.

Devereux Psychiatric Residential Treatment Center
120 David Wade Drive
Victoria, TX 77902-2666
(512) 575-8271 / (800) 383-5000
Res. prog. for those with emotional, behavioral dis. Including a specialized psychiatric hospital/intensive residential treatment program.

Virginia

Faith Mission Home
HCR 1 Box 114
Free Union, VA 22940
(804) 985-2294
Res. care and training center for ambulatory MR or brain-injured children and young adults located in the Blue Ridge Mountains.

SCHOOLS, CAMPS & RESIDENCES

Virginia (cont'd)

Virginia School for the Deaf and Blind at Hampton

700 Shell Road
Hampton, VA 23661

For children who are deaf, blind and multiply disabled with sensory impairment. State residential and day school, scenic campus, modern buildings, certified/endorsed staff, serenely located on the beautiful Eastern Virginia peninsula.

Wisconsin

Chileada Habilitation Institute

1020 Mississippi St.
LaCrosse, WI 54601
(608) 782-6480

Res. treatment ctr. training & intensive therapy for children w/ severe mental & physical disabilities.

St. Coletta School

W4955 Highway 18
Jefferson, WI 53549
(414) 674-4330

Year-round res. prog. in academic instruction and prevocational training for MR/DD. Adult res. facility w/ work opportunities for aging MR/DD.



Is Everyone Focusing On The Negative?

It happens all too often to children with special needs.

At Cotting School, we focus on your child. Building the skills he has. Helping him acquire new ones. And nurturing his self-esteem.

We can build opportunities for your child to view himself positively.

Cotting is a private non-profit, Chapter 766 approved co-educational day school offering educational and therapeutic services to meet a wide range of special needs.

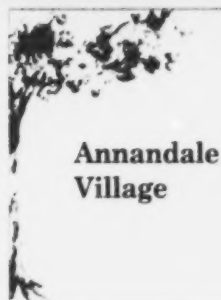
Call us at our new campus in Lexington at (617) 862-7323. Please ask for Department A.

Cotting School

We focus on your child.

For boys and girls with learning, physical, communication or medical needs
453 Concord Avenue, Lexington, MA 02173
(617) 862-7323

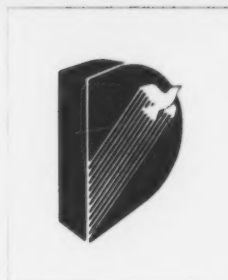
SCHOOLS, CAMPS & RESIDENCES GUIDE



"THEIR COMMUNITY ... WITH OUR HELP" Private, nonprofit community for developmentally disabled adults offering residential / non-residential transitional programs and services.

- Job Training • Arts Activities.
- Therapeutic recreation.
- Case management.
- Founded 1969.
- 125-acre wooded environment.

Contact: **Annandale at Suwanee, Inc.**
3500 Annandale Lane, Box 7
Suwanee, GA 30174
(404) 945-8381



WORKING TOGETHER FOR A BETTER FUTURE! In residential, day and community-based treatment centers nationwide, Devereux provides comprehensive services to individuals of all ages who have:

- Emotional disturbances.
- Developmental disabilities.
- Mental retardation • Dual diagnosis.
- Autism • Post-head trauma.

Contact: National Referral Services
The Devereux Foundation
(800) 345-1292, ext. 3045
(215) 964-3045
(215) 971-4600 (Fax)



BERKSHIRE CHILDREN'S COMMUNITY for children who are severely retarded, multiply disabled.

- Private, nonprofit, residential.
- State-of-the-art campus.
- Intensive therapies.
- Extensive water therapy.
- Advanced medical care.
- Parent assoc. & open-door visiting.
- Nurturing and homelike.

Contact: Gail Charpentier
Berkshire Children's Community
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523



"MAXIMIZING INDIVIDUAL POTENTIAL"

- Community-based, private day / residential treatment.
- Positive behavioral management.
- Ages 8-22, multiply handicapped, mentally retarded, behavior disordered, autistic & hearing impaired.
- 12-month program.
- 10 miles west of Boston.

Contact: Student Services Coordinator
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

RESOURCE SECTION

continued from page 10

NORTH CAROLINA

- Carolina Computer Access Center
Metro School
700 E. Second St.
Charlotte, NC 28202-2880
(704) 342-3004
AppleLink: CCAC

- North Carolina Assistive Technology Project
Dept. of Human Resources
Division of Vocational Rehabilitation Services
1110 Navaho Dr.
Suite 101
Raleigh, NC 27609
(919) 850-2787

NORTH DAKOTA

- Pathfinder Parent Training and Information Center
ATA Computer Resource Ctr.
1600 Second Ave. SW
Minot, ND 58701
(701) 852-9426/9436
AppleLink: PATHFINDER

OHIO

- Ohio Rehabilitative Services Commission
Div. of Public Affairs, SW 4
400 E. Campus View Blvd.
Columbus, OH 43235
(614) 438-1236
- Technology Resource Center, Inc.: Enabling People with Disabilities
2140 Arbor Blvd.
Dayton, OH 45439-1510
(513) 294-8086
AppleLink: CARIS

OKLAHOMA

- Oklahoma Department of Human Services
Rehab. Services Division
DHS, RS #24
P.O. Box 25352
Oklahoma City, OK 73125
(405) 424-4311

OREGON

- Oregon Outback Technology Access Center
111 Elm, P.O. Box 2916
La Grade, OR 97850
(503) 962-7258
AppleLink: OUTBACK
- Oregon TALN Project
Dept. of Human Resources
Vocational Rehab. Division
500 Summer St. NE
Salem, OR 97310-1018
(503) 378-3830, ext.386

PENNSYLVANIA

- Pennsylvania's Initiative on Assistive Tech. (PIAT)
Temple University
Institute on Disability/UAP
423 Ritter Annex
13th Street and Cecil B. Moore Ave.
Philadelphia, PA 19122
(215) 787-1356

SOUTH CAROLINA

- South Carolina Assistive Technology Program
Vocational Rehab. Dept.
P. O. Box 15
1410-C Boston Ave.
West Columbia, SC 29171
(803) 822-5404

SOUTH DAKOTA

- South Dakota Dept. of Human Services
Div. of Rehab. Services
East Highway 34
Hillview Plaza
c/o 500 East Capitol
Pierre, SD 57501-5070
(605) 773-3195

TENNESSEE

- Eastern Tennessee Special Technology Access Center
5719 Kingston Pike
Knoxville, TN 37919-1925
(615) 584-4465
AppleLink: EASTTN
- Technology Access Center of Middle Tennessee
Fountain Square
Suite 126
2222 Metro Center Blvd.
Nashville, TN 37228
(615) 248-6733
AppleLink: TAC
- Tennessee Technology Access Project (TTAP)
Dept. of Mental Health and Mental Retardation
Doctors' Building
Suite 300
706 Church St.
Nashville, TN 37243-0675
(615) 741-7441
- West Tennessee Special Technology Resource Ctr.
Lambuth College
Carney Johnston Hall
401 Maple St.
P.O. Box 3683
Jackson, TN 38303-3683
(800) 464-5619
(901) 424-9089
AppleLink: WESTTN

TEXAS

- SHIP Resource Center
University United Methodist Church
5084 DeZavala Rd.
San Antonio, TX 78249
(512) 822-0995
AppleLink: SHIP
- UAP of Texas
The Univ. of Texas at Austin
Dept. of Special Education
EDB 306-35300
Austin, TX 78712-1290
(512) 471-7621

UTAH

- Computer Ctr. for Citizens with Disabilities
401 Twelfth Ave., Ste. 114
Salt Lake City, UT 84103
(801) 321-5770
AppleLink: CCCD
- Utah Assistive Technology Program
Utah State University
Developmental Center for Handicapped Persons
UMC 6855
Logan, UT 84322-6800
(801) 750-1982

VERMONT

- Vermont Assistive Technology Project
Dept. of Aging and Disabilities
Agency of Human Services
103 S. Main St.
Weeks Building, 1st Fl.
Waterbury, VT 05671-2305
(802) 241-2620

VIRGIN ISLANDS

- Virgin Islands Resource Ctr. for the Disabled, Inc.
P.O. Box 1825
St. Thomas, VI 00803
(809) 777-ABLE (2253)

VIRGINIA

- Virginia Assistive Technology System (VATS)
Dept. of Rehab. Svcs.
Office of Planning
4900 Fitzhugh Ave.
P.O. Box 11045
Richmond, VA 23230
(804) 367-2445
- Tidewater Center for Technology Access
Special Education Annex
273 N. Witchduck Rd.
Virginia Beach, VA 23462
(804) 473-5136
AppleLink: TCTA

WASHINGTON

- Washington Tech. Access Ctr. for Resources and Training
257 100th Avenue NE
Bellevue, WA 98004-5625
(206) 637-9848
AppleLink: START

WEST VIRGINIA

- Project G.L.U.E.
c/o Children's Therapy Clinic
2345 Chesterfield Ave.
Charleston, WV 25304
(304) 342-6501
AppleLink: GLUE
- West Virginia Assistive Technology System
Div. of Rehab. Services
Capital Complex, P.O. Box 50809
Charleston, WV 25305
(304) 766-4698

WISCONSIN

- WisTech
Dept. of Health & Social Svcs.
Div. of Vocational Rehab.
P.O. Box 7852
1 W. Wilson St., Rm. 850
Madison, WI 53707
(608) 267-6720/9599 (TDD)

SOMEONE YOU KNOW

HAS A RARE DISORDER

- That may be fatal or disabling
- That many doctors don't recognize
- That may have no cure or treatment
- That is one of 5000 disorders affecting a total of 20 million people

NORD is a coalition of non-profit agencies, researchers, and individuals that helps by providing information and promoting research. Your membership helps.

NORD



National Organization for Rare Disorders
100 Rt. 37, P.O. Box 8923
New Fairfield, CT.
06812-1783
(800) 999-NORD

MEDIA BUYERS' GUIDE

KEY: ➔ Books for Children ➔ Books for Parents & Professionals
 + Educational Materials ▼ Videotapes ⊗ Audiotapes

➔ **Turtle Books:** for children with disabilities and their friends. Write for free descriptive brochure. Also ask for free brochure "Tips for Selecting Books for Children with Disabilities" for your favorite librarian. **Jason & Nordic Publ.**, P.O. Box 441, Hollidaysburg, PA 16648.

➔ **When Your Child is Seriously Injured: The Emotional Impact on Families** by Marilyn Lash. A 40-page booklet containing practical suggestions and techniques to help parents plan for the future. **\$4.50. Exceptional Parent**, 1170 Commonwealth Ave., Boston, MA 02134.

➔ **When Your Child Goes to School After an Injury** by Marilyn Lash. A 72-page booklet that helps families prepare for their child's entry or return to school after a serious injury. **\$7.50. Exceptional Parent**, 1170 Commonwealth Ave., Boston, MA 02134.

➔ **Hydrocephalus News/Notes.** 20 pg. quarterly newsletter covering research, educ. perspectives, profiles, legislation, neuro-talk, editorials, networking, changing diagnosis/treatments, resources, calendar, interviews, lit. reviews. **\$25/yr.** 1670 Green Oak Cir., Lawrenceville, GA 30243.

➔ **FREE — The NEW Special Needs Project Book Catalog.** Unique selection of the best books from all publishers about disabilities. Comprehensive resource for parents, children & prof. **Special Needs Project**, 1482 E. Valley Rd., #A121, Santa Barbara, CA 93108, (800) 333-6867.

➔ **Free Book Catalog: The 1992 Special Needs Catalog** features a collection of valuable books for children with disabilities and their parents on Down syndrome, CP, autism, spec. ed. and more. Contact **Woodbine House**, 5615 Fishers Ln., Rockville, MD 20852, (800) 843-7323.

+ **Free 1992 Catalog, Toward Independence:** Picture cards and stickers of life skill activities: grooming, housekeeping, shopping, cooking, money-handling and more. Use cards for reminders, list-making and communication. **Attainment Company**, (800) 327-4269.

▼ **"What is Fragile X Syndrome?"** Authored by Ave Lachiewicz, M.D. This is a 15-minute video that describes fragile X syndrome in 9 males. **\$30. Duke University Medical Center**, Fragile X Project, Child Development Unit, Box 3364, Durham, NC 27710.

▼ **Home Tutor Videos.** 5 tapes teach phonics in the comfort of home. Interactive, multimodality approach. Excellent for SLD students. K-2nd grade skills. Challenging and fun! Satisfaction guaranteed. FREE parent/teacher guide & preview. **\$205. Dynamic Lng. Prod.**, (800) 741-0226.

▼ **Interax Video Sign Language Course.** Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. **Free brochure. \$199 plus \$4.50 s&h. Interax Training, Inc.**, P.O. Box 473106, Garland, TX 75047-3106, (800) 242-5583.

▼ **The Beginning American Sign Language VideoCourse.** Learning Sign Lang. is fun & easy with this video! Experience success with Billy Seago as your deaf instructor. **Free catalog. Sign Enhancers**, 1320 Edgewater St. NW, Ste. B-10, EP1, Salem, OR 97304, (800) 767-4461 V/TTY.

▼ **"Say It With Sign" — Emmy Award Nominee.** A video library on signing! Drs. Larry & Sharon Solow romance you to sign with ASL & finger-spelling in 20 hrs. of video! **\$279.50 plus \$6 s&h.** Free catalog, credit cards order today! **Valiant Ed. Videos**, Box 1969, Reseda, CA 91337, (800) 266-2159.

SOFTWARE BUYERS' GUIDE

Software Buyers' Guide is a listing of the newest computer software packages.

Keytalk needs only 6 simple commands to remove barriers to reading and writing. With an Apple Computer and a speech synthesizer, Keytalk "says" what is typed and displayed. **\$115. Jesana Ltd.**, P.O. Box 17, Irvington, NY 10533, (800) 443-4728.

Special Needs Software talking sftwr. in areas of lang. dev., cognitive processing and instructional games. Call for our FREE book, *Sequential Software for Language Intervention*. **Laureate Learning**, 110 E. Spring St., Winooski, VT 05404, (800) 562-6801, (802) 655-4755.

HandiWARE enables improved access to PCs for the mobility-, speech- and hearing-impaired. Works with off-the-shelf prog., generic switches and industry-standard speech synthesizers. **\$20-\$695 plus s&h. Microsystems Sftwr.**, 600 Worcester Rd., Framingham, MA 01701.

MAGic & MAGic Deluxe magnify PC or laptop VGA/SVGA/XGA screen, text & graphics progs. 2x. Deluxe magnifies text-bsd. apps. up to 12x. Work with adapted access sftwr. **MAGic: \$79. Deluxe: \$295 plus \$5 s&h. Microsystems Sftwr.**, 600 Worcester Rd., Framingham, MA 01701.

MARKETPLACE

RATES & INFORMATION:

1X-\$6.00 per word, 4X-\$5.25 per word; 6X-\$4.50 per word. Send your ad & prepayment to: **Exceptional Parent**, 1170 Commonwealth Ave., Boston, MA 02134 or call (800) 853-2864, fax (617) 730-8742.

DIAPERS/INCONTINENCE

ATTENDS® YOUTH BRIEFS

Fits children 35-75 lbs. \$51.95/cs (96). Free Delivery. Also — Depend, Serenity, Other Items. Mfr. Coupons Accepted. Free Catalog. **Access Medical Supply**, (800) 242-2460.

SAVE — FREE CATALOG

Attends®, Tranquility, many brands: youth to large. **HDS**, 325 Paul Ave., Ferguson, MO 63135, (800) 538-1036.

FREE CATALOGUE — Attends®, Tranquility Youth Brief. Free Delivery. Low Prices. Visa/MC. Nat'l. Incontinent Supplies. Call (800) 228-8718.

FEDERAL AGENCIES

These government agencies offer parents and professionals information on services and regulations. The Federal Information Center (FIC) can help you find information about federal government services, programs and regulations. FIC can also tell you which federal agency to contact for assistance. Contact the national FIC for your state's toll-free 800 FIC number at: P.O. Box 600, Cumberland, Md. 21502, (301) 722-9098.

AMERICANS WITH DISABILITIES ACT

American Federation for the Blind and Gallaudet Univ.
(202) 223-0101 (Voice/TDD)

The Arc
(800) 433-5255

Association of Handicapped Student Service Programs in Post Secondary School Education
(800) 247-7752 (Voice/TDD)

Dept. of Transportation
(202) 366-9305
(202) 202-7687 (TDD)

Disability Rights Education Defense Fund
(800) 466-4232 (Voice/TDD)

Equal Employment Opportunity Commission
(800) USA-EEOC
(202) 663-4494 (TDD)

Federal Communications Commission
(202) 632-7260/6999 (TDD)

Office of Fair Housing and Equal Opportunity
(800) 424-8590
(202) 708-4252 (in DC)

Pres. Comm. on Employment of People with Disabilities
1331 F Street NW, Ste. 300
Washington, DC 20004
(202) 376-6200/6205 (TDD)

Regional Disability Business Accommodation Centers
(617) 349-2639/354-6618

U.S. Architectural Transportation Barriers Compliance Board
(800) USA-ABLE

DISABILITY

Administration on Developmental Disabilities
200 Independence Ave. SW
349F Humphrey Building
Washington, DC 20201
(202) 690-6590

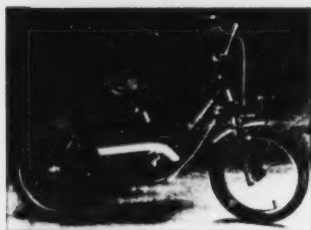
National Information Center for Children & Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013-1492
(800) 999-5599
(703) 893-8614 (TDD)

National Institute of Neurological Disorders and Stroke (NINDS)
9000 Rockville Pike
Building 31, Room 8A-16
Bethesda, MD 20892
(301) 496-5751

National Library Service for the Blind and Physically Handicapped
Library of Congress
1291 Taylor St. NW
Washington, DC 20542
(800) 424-8567
(202) 707-5100

Senate Subcommittee on Disability Policy
113 Hart Senate Office Bldg.
Washington, DC 20510
(202) 224-6265

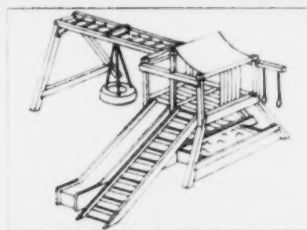
PRODUCT SHOWCASE



The Terrier Tricycle

The Terrier has been designed in close cooperation with therapists. Clear emphasis has been placed on ease of use, appearance, versatility and durability. It has built-in adjustability and can accommodate the most physically challenged rider. It gives important therapeutic exercise and helps promote social integration. Its bright, lively colors and BMX styling leave all other tricycles behind.

Contact: Triaid, Inc.
P.O. Box 1364
Cumberland, MD 21502
(301) 759-3525



Special Playset for Special People

Woodset offers a variety of standard designs coupled with creative solutions to mobility and positioning concerns. Please write or call our Adaptive Equipment Designer. (800) 638-9663 (WOOD).

Contact: Woodset
P.O. Box 2127
Waldorf, MD 20604
(800) 638-9663 (WOOD)



The Dignity Bath

The Dignity Bath Tub from Electric Mobility is the safe, strain-free way to bathe your child. This complete 5' tub has a built-in, water-powered seat lift that gently moves your child in and out of the water — without electricity. Can be installed by any plumber and is available with a therapeutic whirlpool option.

Contact: Electric Mobility Corp.
Dept. 3765
1 Mobility Plaza
Sewell, NJ 08080
(800) 662-4548, ext. 77

FEDERAL AGENCIES

EDUCATION

National Head Start Assoc.
201 N. Union St., Ste. 320
Alexandria, VA 22314
(703) 739-0875

**Office of Special Ed. and
Rehabilitation Services
Clearinghouse on
Disability Information**
U.S. Dept. of Education
Switzer Building
330 C Street SW, Rm. 3132
Washington, DC 20202
(202) 205-8723

GENERAL INFORMATION

**Admin. for Children, Youth
and Families**
330 C Street SW
Washington, DC 20201
(202) 205-8347

Very Special Arts
1331 F Street NW, Ste. 800
Washington, DC 20004
(202) 628-2800
(202) 737-0645 (TDD)

HEALTH

**Health Care Financing
Administration**
Inquiries Staff, Rm. GF-3
East Lowrise Building
Baltimore, MD 21207
Mailing address only.

**Maternal and Child Health
Bureau**
Parklawn Building
5600 Fishers Ln.
Rm. 1805
Rockville, MD 20857
(301) 443-2170

**Medicare/Medigap Info.
and Second Surgical
Opinion Program**
Dept. of Health and
Human Services
Health Care Financing
Administration
Baltimore, MD 21235
(800) 638-6833
(800) 492-6603 (in MD)

**National Center
for Education in Maternal
and Child Health**
38th and R Streets NW
Washington, DC 20057
(202) 625-8400
(202) 625-8410 (hotline)

**Natl. Inst. of Child Health
and Human Development**
Natl. Institutes of Health
9000 Rockville Pike
Building 31, Rm. 2A03
Bethesda, MD 20892
(301) 496-3454

**Office of Disease
Prevention and Health
Promotion**
Natl. Health Info. Center
Natl. Institutes of Health
P.O. Box 1133
Washington, DC 20013
(800) 336-4797

HOTLINES

Consumer Information Ctr.
P.O. Box 100
Pueblo, CO 81002
Mailing address only.

**Consumer Product Safety
Commission**
(800) 638-2772

**District Internal Revenue
Services**
(800) 829-1040 (tax info)
(800) 829-3676 (forms)

FIRS
(Federal Info. Relay Svc.)
(800) 877-8339
(202) 708-9300 (in DC)

SSA Hotline
(Social Security Admin.)
(800) 772-1213
(800) 325-0778 (TDD)

TDD & TTY Operator Svcs.
(800) 855-1155
(202) 708-9300 (in DC)

MENTAL HEALTH

**Mental Health Policy
Resource Center**
1730 Rhode Island Ave.
NW, Suite 308
Washington, DC 20036
(202) 775-8826

**Natl. Assoc. of Psychiatric
Treatment Ctr. for Children**
200 L Street NW
Washington, DC 20036
(202) 955-3828

**National Consortium for
Child Mental Health Svcs.**
3615 Wisconsin Ave. NW
Washington, DC 20016
(202) 966-7300

High- Performance Therapy

The Tumble Forms Ready Racer
looks like a lot of fun. And it is.
But it's also a whole lot more.

The Ready Racer is a vehicle for
therapy that helps special needs
kids develop perceptual motor
skills, trunk control, and upper
body strength and coordination.

Put your child in the driver's seat.
(Then yield the right of way.)



**Tumble
Forms**

Ready Racer

Preston

Accessible Theme Parks

The following is a list of some of the more popular theme parks in the U.S. and their accessibility to visitors with disabilities. In most cases, parks have a limited number of wheelchairs available for rental on a first come, first served basis. Most park personnel can offer information and assistance but are not trained to assist guests with disabilities and are therefore not allowed to help with boarding or disembarking from rides. Most parks offer accessibility guides and recommend that guests with disabilities be accompanied by someone who can assist them while visiting the park.

- ▼ = Accessible Restrooms ➡ = Guide Dogs Allowed
 ☎ = Accessible Telephones ◆ = Wheelchair Accessible Parking
 + = First Aid \$ = Manual/Electric Wheelchair Rental

Busch Gardens — Dark Continent

P.O. Box 9158
 Tampa Bay, FL 33674
 (813) 987-5000
For Explorers With Special Needs brochure outlines park accessibility and policy.
 ▼ + ➡ ◆
 \$ = \$3.50/manual + \$1 deposit

Busch Gardens — The Old Country

P.O. Box Drawer FC
 Williamsburg, VA 32187
 (804) 253-3350
 ▼ + ➡ ◆
 \$ = \$4/manual; \$20/electric

Disneyland

c/o Information
 1313 Harbor Blvd.
 Anaheim, CA 92803
 (714) 999-4565
 (714) 999-4569 (TDD)
 TDDs; complimentary cassette tapes and portable tape player for guests with hearing impairments; *The Disneyland Disabled Guest Guide* details park accessibility and policy.
 ▼ + ➡ ◆
 \$ = \$5 + \$20 deposit

Oceans of Fun/ Worlds of Fun

4545 Worlds of Fun Avenue
 Kansas City, MO 64161
 (816) 454-4545
 Ext. 1120
 Attraction accessibility and park policy guide available at Guest Relations.
 ▼ + ➡ ◆ (Both parks)
 \$ = Free/manual + \$25 deposit (Both parks)
 \$ = \$25/electric (at Worlds of Fun only)

Sea World

7007 Sea World Drive
 Orlando, FL 32821
 (407) 351-3600
 ▼ + ➡ ◆
 \$ = \$5/manual; \$25/electric

Six Flags Great Adventure

Rt. 537
 Jackson, NJ 08527
 (908) 928-2000
 TDDs and phones with amplifier buttons available for people with hearing impairments; *Guest Accessibility Guide Book* details park accessibility and policy.
 ▼ + ➡ ◆
 \$ = Free

Six Flags Great America

P.O. Box 1776
 Gurnee, IL 60031
 (708) 249-1776
 Free Admission to guests in wheelchairs; reduced admission (\$12.95) to guests with other disabilities; *Accessibility Brochure* available.
 ▼ + ➡ ◆
 \$ = fee not yet determined

Six Flags Magic Mountain

P.O. Box 5500
 Valencia, CA 91385
 (805) 255-4100
 Reserved seating available for guests in wheelchairs at all theaters and show venues; *Handicap Guide* available detailing ride accessibility and park policy.
 ▼ + ➡ ◆
 \$ = \$2 + \$5 deposit/manual & electric

Six Flags Over Georgia

Attn: Public Relations
 P.O. Box 43187
 Atlanta, GA 30378
 (404) 739-3400
 Reduced Admission available, based on individual limitations; *Disabled Guest's Guide* details park accessibility and policy.
 ▼ + ➡ ◆
 \$ = \$6/manual; \$25/electric

Six Flags Over Mid-America

P.O. Box 60
 Eureka, MO 63025
 (314) 938-5300/4805 (TDD)
Accessibility Guide available.
 ▼ + ➡ ◆
 \$ = \$5/manual + \$20 deposit

Six Flags Over Texas

P.O. Box 191
 Arlington, TX 76010
 (817) 640-8900
Wheelchair Guide available.
 ▼ + ➡ ◆
 \$ = \$6 manual

Universal Studios — Florida

Guest Relations
 1000 Universal Studios Plaza
 Orlando, FL 32819
 (407) 363-8000/8265 (TDD)
 Wheelchair Accessible indoor dining and shopping; TDD at Guest Relations; *Studio Guide For the Disabled Guest* details accessibility of rides/attractions.
 ▼ + ➡ ◆
 \$ = \$5/manual; \$25/electric

Universal Studios — Hollywood

100 Universal City Plaza
 Universal City, CA 91608
 (818) 777-3801/8559 (TDD)
 Temporary Handicapped Parking Passes available for rental cars; wheelchair accessible water fountains, shopping and dining; Audio-Assist Units available for guests with hearing impairments; *Disabled Guest Guide* details park accessibility and policy.
 ▼ + ➡ ◆
 \$ = \$3/manual (18" and 20")

Walt Disney World Resort

(Epcot Center, Disney-MGM Studios Theme Park, Magic Kingdom)
 P.O. Box 10,000
 Lake Buena Vista, FL 32830
 (407) 828-1258
 Special-Lift Equipment buses; TDDs; amplified handsets; free use of cassette tapes and portable tape player for guests with hearing impairments; some attractions offer personal translator units to amplify audio; *The Walt Disney World Disabled Guests Guide Book* details Disney's attraction accessibility and park policy.
 ▼ + ➡ ◆
 \$ = \$3/manual + deposit



CRUISER WARRANTY

5 YEARS or 50,000 MILES

WHICHEVER COMES FIRST



Recently, a customer sent her son's Cruiser back to us for some minor adjustment. We wanted you to see the chair after five years of hard use. It still looks and works like new. This is why we can offer an exclusive five-year warranty. Don't worry — we won't hold you to the 50,000 miles!*

Our new Cruisers are even better. They are more adjustable so they can grow with the child, and over 20 positioning features are available from a full range of



Cruiser, after 5 years . . .

accessories. And, best of all, they're lightweight and easy to fold. Convaid also offers the Cruiser Transport, a bus/van tie-down model for kids on the go.

For more information call Convaid today!

(800) 552-1020

Imagine the possibilities . . .

Convaid
PRODUCTS INC

P.O. Box 2458, Palos Verdes, CA 90274
(310) 539-6814 • Fax: (310) 539-3670

Made in the USA

*Complete warranty information provided upon request.



Wheelchair Accessible National Parks

This directory includes national parks with wheelchair access to campsites, restrooms and visitor centers. Parks marked with an asterisk (*) have at least one self-guiding tour or trail.

From The National Park System Map & Guide, National Park Service, U.S. Dept. of the Interior, 1990.

ALASKA

**Denali National Park and Preserve*
Accessibility Coordinator
P.O. Box 9
McKinley Park, AK 99755
(907) 683-2294
(907) 271-2716 (TDD)

ARIZONA

**Grand Canyon Natl. Park*
Special Populations Coordinator
P.O. Box 129
Grand Canyon, AZ 86023
(602) 638-7769
(602) 638-7772 (TDD)

ARKANSAS

**Hot Springs National Park*
Special Populations Coordinator
P.O. Box 1860
Hot Springs, AR 71902
(501) 624-3383

CALIFORNIA

**Death Valley National Monument*
Death Valley, CA 92328
(619) 786-2331

**Sequoia National Park*
Chief Park Interpreter
Three Rivers, CA 93271
(209) 565-3341

**Yosemite National Park*
Public Information Officer
P.O. Box 577
Yosemite N.P., CA 95389
(209) 372-0265
(209) 372-4726 (TDD)

COLORADO

**Mesa Verde National Park*
U.S. Dept. of the Interior
National Park Service
Mesa Verde N.P., CO 81330
(303) 529-4465

**Rocky Mountain Natl. Park*
Public Information Officer
National Park Service
Estes Park, CO 80517
(303) 586-2371
(303) 586-8506 (TDD)

FLORIDA

**Everglades National Park*
P.O. Box 279
Homestead, FL 33090
(305) 247-6211 (Voice/ TDD)

HAWAII

**Hawaii Volcanoes National Park*
Hawaii N.P., HI 96718
(808) 967-7311

KENTUCKY

**Cumberland Gap National Historical Park*
P.O. Box 1848
Middlesboro, KY 40965
(606) 248-2817

MAINE

**Acadia National Park*
P.O. Box 177
Bar Harbor, ME 04609
(207) 288-3338

MARYLAND

**Antietam Natl. Battlefield*
Box 158
Sharpsburg, MD 21782
(301) 432-5124

MICHIGAN

**Pictured Rocks National Lakeshore*
P.O. Box 40
Munising, MI 49862
(906) 387-2607

MISSISSIPPI

**Natchez Trace Parkway*
R.R. 1 — NT-143
Tupelo, MS 38801
(601) 842-1572

MISSOURI

**Ozark National Scenic Riverways*
P.O. Box 490
Van Buren, MO 63965
(314) 323-4236

MONTANA

**Glacier National Park*
Special Pop. Coordinator
National Park Service
West Glacier, MT 59936
(406) 888-5441/5790 (TDD)

NEVADA

**Great Basin National Park*
Baker, NV 89311
(702) 234-7331

**Lake Mead National Recreation Area*
601 Nevada Highway
Boulder City, NV 89005-2426
(702) 293-8920

NEW YORK

**Fire Island National Seashore*
120 Laurel St.
Patchogue, NY 11772
(516) 563-8448

NORTH CAROLINA

**Blue Ridge Parkway*
700 Northwestern Plaza
Asheville, NC 28801
(704) 259-0779

OKLAHOMA

**Chickasaw National Recreation Area*
P.O. Box 201
Sulphur, OK 73086
(405) 622-3165

OREGON

**Crater Lake National Park*
P.O. Box 7
Crater Lake, OR 97604
(503) 594-2211

SOUTH DAKOTA

**Wind Cave National Park*
Superintendent
National Park Service
Hot Springs, SD 57747
(605) 745-4600

TENNESSEE

**Big South Fork National River and Recreation Area*
P.O. Drawer 630
Oneida, TN 37841
(615) 879-3625

**Great Smoky Mountains National Park*
Chief of Visitor Services
National Park Service
Gatlinburg, TN 37738
(615) 436-5615

TEXAS

**Big Bend National Park*
Public Information Officer
U.S. Department of the Interior
Big Bend National Park, TX 79834
(915) 477-2251
(915) 477-2370 (TDD)

TEXAS (cont.)

**Padre Island National Seashore*
9405 S. Padre Island Dr.
Corpus Christi, TX 78418-5597
(512) 937-2621

UTAH

**Arches National Park*
Superintendent
National Park Service
P.O. Box 907
Moab, UT 84532
(801) 259-8161

**Bryce Canyon National Park*
Superintendent
National Park Service
Bryce Canyon, UT 84717
(801) 834-5322 (Voice/TDD)

**Zion National Park*
Superintendent
National Park Service
Springdale, UT 84767-1099
(801) 772-3256

VIRGINIA

**Shenandoah Natl. Park*
Accessibility Coordinator
Rt. 4 — Box 348
Luray, VA 22835
(703) 999-2243

WASHINGTON

**Olympic National Park*
Special Populations Coordinator
600 E. Park Ave.
Port Angeles, WA 98362
(206) 452-4501

WISCONSIN

**St. Croix and Lower St. Croix National Scenic Riverways*
P.O. Box 708
St. Croix Falls, WI 54024
(715) 483-3284

WYOMING

**Grand Teton National Park*
VIP Coordinator
P.O. Drawer 170
Moose, WY 83012
(307) 733-2880

**Yellowstone National Park*
Special Populations Coordinator
Mammoth Headquarters
P.O. Box 168
Yellowstone National Park, WY 82190
(307) 344-7381

"The best lift is no lift"



Take a commanding view of the road in a Vantage modified Chrysler mini van. Wheelchair and scooter users enjoy **total independence** with the fully automated Persona model.

With the simple touch of a button, the power door opens and the ramp gently lowers to the ground. Wheelchair and scooter occupants enter and exit the vehicle effortlessly with the low angled ramp. For **full versatility**, the front seat is removable and can be installed in either the driver or front passenger seating positions.

Standard features on the Vantage Persona conversion include a lowered floor, power door and power ramp with swing away ramp feature, "kneeling" air suspension, and a removable front seat. In addition, each Vantage conversion comes complete with such **safety features** as steel fuel lines, brass air fittings, and rear collision protection bars. Complete rust protection, rubberized undercoating and sound deadening are also included on each van at no additional cost.

Vantage vehicles are safety tested. Each vehicle passes strict quality and safety requirements. Our conversions are built to last and are backed by the **most extensive warranty** in the industry. Service, parts, and warranty support are available from our nationwide dealer network.

For an informative brochure on the Persona and other Vantage models, call our **toll-free number**. We will put you in touch with a Vantage dealer near you.

VANTAGE
MINI  VANS

1-800-348-VANS

2441 E. Chambers St., Phoenix, AZ 85040

Tumble Forms® TriStander™



Vertical



Prone



Supine

Triple Your Therapy Options

The new TriStander™ from Tumble Forms® does the job of three standers. Its unique design allows vertical, prone, or supine standing, so you can count on a single stander to meet a variety of positioning needs. The height-adjustable positioning modules accommodate children from 32 to 47 inches tall, so you can use it with a number of pediatric clients, or let it "grow" with a single patient. And because one stander does it all, you save valuable floor space, as well as money!

Preston

A BISSELL HEALTHCARE COMPANY

For more information call:
1-800-631-7277

P.O. Box 89, Dept. 1331, Jackson, MI 49204-0089

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February 1993
\$4.00

EXCEPTIONAL PARENT
PARENTING YOUR CHILD WITH A DISABILITY

Annual Income Tax Guide



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51

THE POWER TO GROW.



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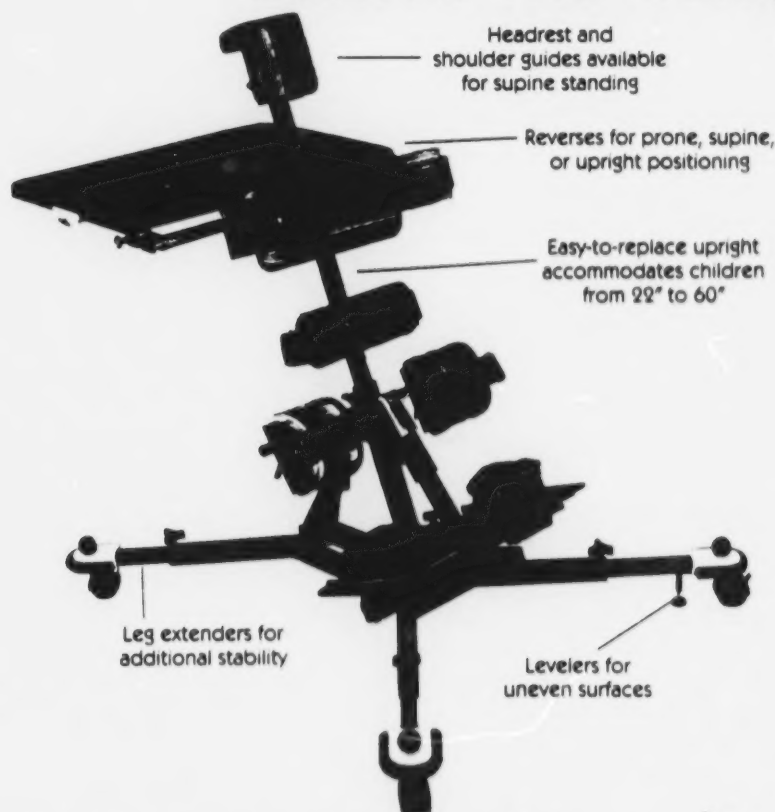
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Exceptional Parent



Cover: Smiling Sisters. Kimber, 5, and Julie Schultz, 10, of Lake Villa, Ill. Julie's Family Album appears next issue.

February 1993

Volume 23, Number 2

- 20 Profound Truths** by Kathleen M. Fagley
A family's decision to place their son in a residential home.
- 24 Circle of Friends** by Nancy Boatwright
A teenager's Circle of Friends helps make her inclusion transition easier.
- 28 Family Hall of Fame** *Exceptional Parent* inducts Edwin Martin for his legislative advocacy over the past 20 years.
- 30 Coping with Incontinence** by Katherine F. Jeter
How parents can help their children understand and deal with incontinence.
- 36 School Mainstreaming Contest Winners, 1992**
Southwest Middle School, Florida; Also: Commendations — Benson Memorial Preschool, N.C. and Pasadena Unified School District, Calif.
- 38 Annual Income Tax Guide**
Tips to help parents of children with disabilities file their federal income taxes.
- 42 On the Ice** by Mary Greenlaw
A mother reflects on her journey to accepting her son's disability.
- 46 1992 Article Index** *Exceptional Parent's* 1992 articles listed by subject.



Page 24



Page 20

- 8 Family Support** Letters to the Editors, Parents Search, Parents Respond
- 14 Editorial** A Letter to President Clinton
- 44 Resource Section** A list of useful toll-free information numbers.
- 45 Technology Bulletin Board** ATA Scrapbook of Success.
- 48 Family Life** Family problems when professionals disagree.
- 52 From the Bookshelf** One Miracle at a Time: Getting Help for a Child with a Disability
- 55 What's Happening** International exchange program; youth digest; RESNA conference; ADA info; accessible camping holidays abroad and more!
- 66 Fun Stuff** by Alice Wershing Drawing with Spirograph Suspension Art,™
- 68 Family Album** by Drew A. Evans My Sisters



Page 42

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 9 times per year (Jan, Feb, Mar, Apr, June, July, Sept, Oct, Dec) by Psy-Ed Corporation, 1170 Commonwealth Ave., 3rd floor, Boston, Mass. 02134-4646. All rights reserved. Copyright ©1993 by Psy-Ed Corporation. "EXCEPTIONAL PARENT" "Exceptional Parent" is a registered trademark of the Psy-Ed Corporation.

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In this new year, many people are looking to the future with optimism as we begin a new presidential administration. We are especially hopeful because President Clinton recently reaffirmed his strong commitment to "full implementation and enforcement of the ADA." We discuss our hopes for the new administration in our editorial, *A Letter to President Clinton*.



Stanley D. Klein



Maxwell J. Schleifer

School Decisions. For most families, choosing whether a day or residential school will meet their child's needs is a difficult decision. In *Profound Truths*, Kathleen Fagley discusses her family's decision to place her son in a residential home. At the same time, in *Circle of Friends*, Nancy Boatwright tells the story of her teenage daughter Amy's inclusion process and how classmates volunteered to help make her transition more rewarding for all concerned.

We close out our 1992 School Mainstreaming Contest by honoring Southwest Middle School in Orlando, Fla., and giving commendations to Benson Memorial Preschool, Raleigh, N.C., and Pasadena Unified School District, Pasadena, Calif. We look forward to another record number of nominations this year.

Congratulations. We congratulate *Exceptional Parent Family Hall of Fame* member Jackie Brand on recently receiving the prestigious 1992 Betts Foundation Award. Brand, founder of the Alliance for Technology Access, was cited for meeting the real challenges of people with disabilities and succeeding because of her "unrealistic" high expectations for her daughter and hundreds of thousands of other Americans living with physical disabilities.

Brand's daughter Shoshana, who has cerebral palsy and limited vision, will graduate from high school this year with the rest of her class. "The motivating force behind the ATA was Jackie Brand's motherly instincts about her daughter's abilities," said Betts Award jury chairman Robert W. Galvin.

The Betts Award is presented annually to an outstanding individual who has improved the quality of life for people with physical disabilities. It is a powerful reminder that one person can make a difference.

Annual Guide to Products and Services. We have already received many positive responses to our first *Annual Guide to Products and Services*. We plan to continue serving our readers by providing additional buyers' guides throughout the year. This issue we include buyers' guides for incontinence products and schools, camps and residences. We welcome feedback from our readers on these guides.

INDEX TO SPECIAL ADVERTISING SECTIONS

SECTION	PAGE #'S	SECTION	PAGE #'S
Incontinence Buyers' Guide	31	Media Buyers' Guide	54
Marketplace/Advertisers Index	39	Schools, Camps & Res. Directory	56, 57
Product Showcase	41	Schools, Camps & Res. Guide	60

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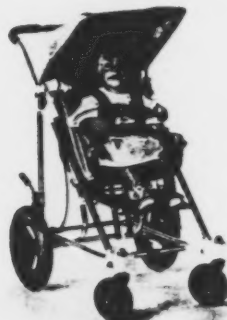
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MIC-KEY Puts Parents in Control

A new skin level gastrostomy device, Medical Innovations Corporation's "MIC-KEY," puts PARENTS IN CONTROL! A growing number of children are unable to eat enough by mouth to gain weight and stay healthy. Many of these children require gastrostomies in order to safely give them the nutrition they need to grow, develop, and fight off infection.

Gastrostomies have been used many times over the past one hundred years and the tubes used are usually bothersome to children and families. Until now, the typical tube used for gastrostomies is long, easily pulled out, needs to be secured, and is hard to hide under clothes. These tubes can now be replaced by a skin-level device (MIC-KEY) that parents can easily and safely insert at home.

The MIC-KEY gastrostomy device was designed specifically with children in mind. There are many positive features about the MIC-KEY gastrostomy device and our clinical experience over the past year proves that it is the best choice for a safe, non-traumatic, easy to care for gastrostomy.

• **EASY and Non-Traumatic Insertion** — The MIC-KEY can be safely placed after a PEG or traditional gastrostomy tube. It can be inserted by parents or home health nurses and does not require a visit to the doctor or Emergency Room for replacement. It is inserted just like a gastrostomy tube.

• **EASY and Secure Feeding System** — No more accidents with formula leaking from the feeding set. Unlike other products, the MIC-KEY skin level gastrostomy has a new and improved "lock-in-place" feeding tube so that the feeding goes into the child and not on the bed or clothing. This is especially important with little ones that pull at their tubes. Medical Innovations Corporation listened to parents who said that this was a problem, and fixed it!! There are short medication feeding sets that are available also.

• **EASY and Adjustable Sizes** — Unlike the others, the MIC-KEY is designed to fit your child's abdomen. The numerous lengths (over 13) and the internal balloon make it possible to fit any size child well. No more problems with gastric leakage due to a button not fitting well and no more "in-between" sizes problems that often occurs with a button.

• **EASY Gastric Decompression** — If your child has problems with gas or with air in the stomach, it is very easy to "vent" or "burp" through the MIC-KEY skin level gastrostomy. Many children who could not handle a button before can now have the comfort of a skin level feeding device.

• **EASY to Care For** — The MIC-KEY has been described by one young customer as a "flying saucer on a stick." The softness of the MIC-KEY dome helps it to fit snugly on your child's stomach while the internal balloon volume prevents stomach contents from coming out onto the skin. The site is easily seen and no dressing or anchoring device is necessary as the MIC-KEY cannot move around.

• **EASE and Comfort** — Many people feel that a skin level device is more comfortable and helps the child to grow and develop better. Because they are more comfortable on the bellies, children seem to be able to move easier. Professionals may be intimidated by a tube; but they won't even see the MIC-KEY under your child's clothes.

We hope that you will try the MIC-KEY because it is just EASY. We want to make the care of your child as easy as we can for you.

TESTIMONIALS

"Just a note to say thank you for developing the MIC-KEY G-Tube. I am a parent of a one-year-old baby girl. She is unable to eat by mouth at this time. She had a nasal tube before she got her MIC-KEY and daily life was miserable for her and for me! She now has been on the MIC-KEY for two months and what a difference. She is smiling, happy and eating without throwing up all the time. She is gaining weight and it is so easy to use and clean. You certainly have made my life easier as your motto says! Thank You."

— Mrs. Valerie Engelmann, Gig Harbor, WA

"The MIC-KEY has proven to be a great help for both my child Ryan and myself."

— Tracy Jones, R.N, Chesapeake, VA

"In the past, we've tried the other button but the MIC-Key's locking feeding system works best for my active toddler, Tesa. No more cleaning up of wasted formula and changing wet clothes. My daughter and I are both much happier with the MIC-KEY."

— Mrs. Karen Froggate, Virginia Beach, VA

Letters to the Editors

No Alternative to Coping

"Is our house bigger than that one? What about that house?" asks my five-year-old son as I drive him to school along a street of beautiful, stately homes.

Don't we all have a little of my son's attitude? Wanting whatever we have to be the biggest, the best; wanting to brag about our children and our possessions.

What happens when a child has extra needs and is somewhat different from his peers? How does a parent learn to live with a predicament which conflicts with the desire to brag about having the "best?"

The facts in my case are parenting two children who require therapy and special-needs environments. Yes, I could brag about their progress, but their medical problems are not something I discuss with everyone.

The desire to brag about parenting the perfect child is only part of the pain for a parent who discovers that her child has different needs than most children. Denial, anger, envy and a feeling of being cheated are all emotions I have experienced.

Endless trips to therapists and doctors, slow progress, tons of paperwork from professionals and multitudes of bills and insurance forms are the lot of parents of children with extra needs.

How does a parent learn to live with the realization that her child has more medical and therapeutic needs than most children?

I realize there is no alternative to coping. Who else will take the children to all of their appointments and care enough to keep tabs on

what the professionals are doing? My husband is working hard to pay our bills. Who else will sort out the bills and insurance claims? Who else will give love and support?

So when things get rough, I'll just grit my teeth, eat something loaded with chocolate and learn to live with it.

J.P.
Georgia

Appearances Do Count — That's the Problem

Helen Reisner says in *Appearances Count* (Networking, September 1992) that, "We must not allow barriers of socially unacceptable behaviors and personal hygiene to prevent full inclusion." She wants us to take responsibility for seeing that persons with disabilities are socially acceptable. She says she wants to "go back to basics" and reminds us that "appearances count."

Her approach to obtaining full inclusion relies on altering people until they meet current standards of social acceptability. That's not enough.

In some cases it is possible, although not necessarily practical or personally desirable, to do what Reisner suggests. She forgets that not all socially unacceptable characteristics can be altered to meet current standards. What happens to full inclusion in these cases?

Appearance does count. That is the problem, not the solution. Let's really go back to basics. We have defined much of social acceptability in terms of what a person looks like, and the list of acceptable characteristics has been rather short.

The length of the list of acceptable characteristics is the real barrier to full inclusion. Full inclusion comes when we redefine social acceptability to say, "Appearances don't count. You are fine just the way you are."

Reisner accepts that appearance counts, takes responsibility for

creating acceptable appearances and hopes that reducing the number of socially unacceptable characteristics a person has will gain that person inclusion into a group.

However, some of us rage at the short list of acceptable appearances, take responsibility for expanding the list to include behaviors and "personal hygiene" that accompany disability and fight for full inclusion of those unalterable persons who are now deemed unacceptable.

Reisner wiped drool off a communication device to make a therapist more comfortable. My son's therapist wiped drool off a communication device to make it easier for him. She also routinely hugged him, drooled and all, because she liked him. We should think about which approach is more likely to promote full inclusion.

C.G.
Missouri

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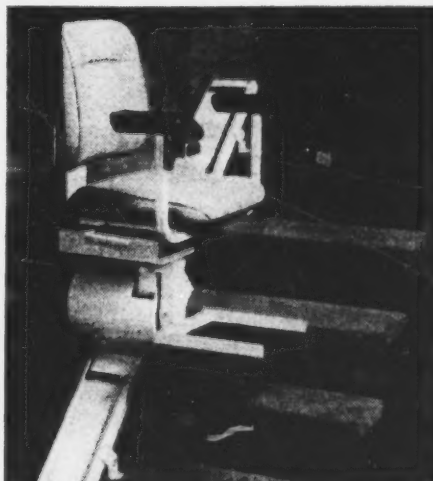
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Parents Search

Alternative Treatment for Gum Swelling?

Our 19-month-old daughter, Samantha Joy, has multiple disabilities caused by a birth injury. She has a tracheostomy and a G-tube for feeding. She has been taking phenobarbital for a seizure disorder since she was six weeks old. She was also taking Dilantin until she developed a

complication called gingival hyperplasia at age 11 months.

The Dilantin caused her gums to swell so much that her teeth are unable to cut through fully. Parts of her front teeth are peeking out, but they are surrounded and grasped by the overgrown gums.

Previously we were under the impression that the swelling would



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F.Y.I.

An Overview of Cerebral Palsy

Cerebral palsy is a condition caused by damage to the brain, usually occurring before, during or shortly following birth. "Cerebral" refers to the brain and "palsy" to a disorder of movement or posture. It is neither progressive nor communicable, nor is it curable in the accepted sense, although training and therapy can help. People with cerebral palsy manage their condition. It is not a disease and should never be referred to as such.

Cerebral palsy is characterized by an inability to fully control motor function. Depending on which part of the brain has been damaged and the degree of involvement in the central nervous system, one or more of the following may occur: spasms; involuntary movement; disturbance in gait and mobility; seizures; abnormal sensation and perception; impairment of sight, hearing or speech; and, in about 20 percent of people with cerebral palsy, there may be some degree of mental retardation.

It is roughly estimated that currently about 3,000 to 5,000 infants are born with the condition each year, and some 500,000 to 700,000 children and adults in the United States manifest one or more of the symptoms of cerebral palsy. Measures of prevention are increasingly possible today, however.

Any damage to the brain, whether caused by defective development, injury or disease, may produce cerebral palsy. Chief among the causes is an insufficient amount of oxygen reaching the fetal or newborn brain. Oxygen supply can be interrupted by premature separation of the placenta from the wall of the uterus, an awkward birth position, labor that is either too long or too abrupt or interference with the umbilical cord. Other causes may be associated with premature birth, Rh or A-B-O blood type incompatibility between parents, infection of the mother with German measles or other viral diseases in early pregnancy and microorganisms that attack the newborn's central nervous system.

Management of cerebral palsy consists of helping the child achieve maximum potential in growth and development. This should be started as early as possible with identification of the very young child who may have developmental disorders. A management program can then be started promptly to include attention to the child's movement, learning, speech, hearing, social and emotional development.

Resource: *Cerebral Palsy — Facts and Figures* was produced by the United Cerebral Palsy Association, Inc. This excerpt was reprinted with permission from the UCPA, 1522 K Street, NW, Washington D.C. 20005, (800) 872-5827.

gradually disappear after the medication was discontinued. Now we are told that there was a change in the chemistry of the tissue and the overgrowth has to be surgically removed under general anesthesia.

Samantha has been through so much already that we are hesitant about having her endure yet another surgical procedure. We are wondering if any other parents have had this problem and could offer some advice.

B.B.
Illinois

CHARGE Association/ Toilet Training

My five-year-old son was diagnosed with CHARGE association a year ago. This is a very rare condition. I took him to several specialists who had diagnosed him to be developmentally delayed until 1991.

A.J. is delayed in his gross motor skills. He started walking between the ages of three and four. Currently, he still falls many times and his gait is unsteady.

He has been receiving occupational, physical and speech therapy since he was 18 months old. He has severe hearing loss and wears bilateral hearing aids. He attends a nursery for deaf children under special education. He was tested twice by two different psychologists last year and they determined that he does not have mental retardation.

His teacher and I are concerned that A.J. is not yet toilet trained. I tried unsuccessfully, and I really don't know if the cause is psychological or behavioral. I would like to hear from another parent with a similar child.

J.P.T.
Illinois

Alternating Hemiplegia

Our four-year-old son was diagnosed with alternating hemiplegia which causes one side of his body to become paralyzed for a short time. There are also times when he becomes totally paralyzed and cannot eat, drink, etc. This condition is very frustrating because you never

know what is going to happen with him from day to day.

We have so many questions. We cannot find any other children with this condition. We would like to hear from anyone with a similar condition.

R.C.
Indiana

Teen Pen Pals Wanted

I am an articulate 14-year-old girl with cerebral palsy. I use an electric wheelchair. I never could walk. I would like to be pen pals with an intelligent girl who is in a similar situation. I would like to share what having cerebral palsy is like for me. I would also like to know what it's like for someone else. I would like someone to compare notes with and to be my friend.

I would like to correspond with someone who is able to speak and write fairly well. It doesn't matter what her interests are, but she must write long, detailed letters. I would

prefer pen pals between the ages of 13 and 15.

J.A.
Vermont

Career Concerns for Teens with Cerebral Palsy

We have a lovely 13-year-old daughter who was born prematurely and has cerebral palsy. She is wheelchair mobile but can walk short distances with a walker. Jennie is very bright and is in the gifted and talented program in her junior high school.

Jennie has high expectations for her future — she wants to be a lawyer. She has, however, recently expressed concern because she has never met a successful business person who uses a wheelchair, unless they already had a career and became disabled because of an accident.

We would like to hear from families who have a child with a similar disability who is close to Jennie's age. We live in a very rural

continued on page 16

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Parents Respond

Placement Decision

Response to G.H. & R.H.'s Parents Search, November/December 1992.

We are the parents of a three-year-old daughter with multiple disabilities. Keelin suffered a stroke "in utero" which resulted in a seizure disorder, mental retardation, cortical blindness and cerebral palsy. Keelin was placed in a pediatric nursing

home one year ago. It was the hardest decision we ever made.

The best advice I can offer you is what another mother said to me. "Your daily living will get easier." I still struggle with guilty feelings, but I know that in the long run, placement was a wise decision.

We checked out three types of residences — group home, medical

foster care and pediatric nursing home. The nursing home was our choice because it is located close to our home.

We didn't have to change any of Keelin's doctors and it really isn't a sad place. We see Keelin at least once a week and try to bring her home for a day on weekends, and I also call every day.

It's a hard decision to make and one you should never feel guilty about. I hope this helps.

C.G. & P.G.

Massachusetts

Editors' Note: Please also see the related feature article *Profound Truths* on page 20 of this issue.

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Eating Disorder

Response to T.S.'s Parents Search, October 1992.

We just adopted our four-year-old son, Carl, who has developmental delays and eating problems. He still doesn't chew and we have been told this is due to his cerebral palsy and lack of muscle control. He can't tolerate textures. We have tried many ideas with Carl, and his progress is consistent but very slow.

We began by wrapping a wash cloth around an index finger and rubbing his teeth, gums, tongue and the inside of his cheeks. He gagged a lot at first but is a lot better now. We bought a soft-bristle toothbrush and sponge mouth swabs and did the same thing with those.

At home, he eats whatever we eat. We smash it up with a fork or use our blender. Instead of putting the spoon in his mouth, we put it right in front of his lips and have him use his top lip to pull it off.

Anything we can roll into small balls we place on his bottom back teeth, push up on his jaw and make him chew or he has to use his tongue to get it off.

We also put a lollipop at the corners of his mouth and show him how to stick his tongue out to lick it. Then we move the lollipop to his chin to get him to reach down with his tongue to lick it.

Please don't get discouraged.

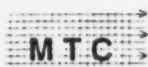
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A Letter to President Clinton

DEAR PRESIDENT CLINTON,

Congratulations and best wishes as you take on the awesome responsibilities of leadership.

Throughout the Presidential campaign as well as during the transition period, you demonstrated an impressive breadth of knowledge about the complicated issues that face our country. Now you take on the challenge of applying your understanding to the process of change.

In your campaign statement in *Exceptional Parent* (October 1992), you showed that you were aware of the vast changes that have been taking place in the lives of children and adults with disabilities and their families. At the same time, you made clear your goals to bring the promise of legislation like the Americans with Disabilities Act to the reality of everyday community life for all citizens with disabilities — "My administration's disability policies will be based on three simple creeds: inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism. ... This theme of empowerment, inclusion and independence means providing education and job training so Americans with disabilities can actively contribute to our country's productivity. It means providing quality, affordable, comprehensive health care that accommodates the special health needs of Americans with disabilities ...

"For too long, education and training for Americans with disabilities has been underfunded and pushed outside of national efforts. I will work to make sure that children with disabilities receive a first-rate education, tailored to their unique needs but provided alongside their nondisabled classmates. My administration will fully fund the Head Start program and other early intervention programs that will assist children with disabilities."

The remarkable advances that have occurred over more than two decades are the results of the efforts of parents of children with disabilities and people with disabilities, as well as dedicated leaders from both political parties. The enactment of the Americans with Disabilities Act is the most recent statement regarding the basic tenant of equality of opportunities for all Americans. This concept did not mean much to most children and adults with disabilities until a courageous group of parents with children in state institutions for people with mental retardation took on the state of Pennsylvania more than 20 years ago.

Today, as all of us know too well, opportunities for

quality education and quality health care for all children (not just children with disabilities) vary widely from community to community and from state to state. In both health care and education, providing adequate resources when needs are first identified can decrease the need for vast resources in the future. For most children with disabilities, quality health care and quality education are intertwined far more than for most children without disabilities. For many families of children with disabilities, health-care costs have been overwhelming in terms of actual dollars spent. In addition, parents are forced to give up employment opportunities because they are afraid of losing whatever health insurance they already have or the appropriate health or educational services available in one location but not in another. Therefore, thousands and thousands of parents of children with disabilities eagerly await your proposals in both health care and education with the hope that you can reach the goal of "providing quality, affordable, comprehensive health care that accommodates the special health needs of Americans with disabilities."

Just as millions of children and adults have become cognizant of the need to address the health and care of the environment and are making changes in their current lives based on long-term payoffs, you and your administration can educate our citizens so they can learn to appreciate the moral as well as long-term fiscal payoffs involved when all children have quality health care, comprehensive early intervention and quality education. Such a national educational process requires a skilled team of government officials involved in monitoring and facilitating compliance with existing laws at the state and local level related to children and adults with disabilities. We believe that quality health care and quality education programs for children with disabilities have suffered in recent years because the federal government has decreased its efforts to monitor and facilitate compliance.

We are ready to help you and your administration educate our citizens. We invite you and the members of your administration to use these pages to educate thousands of parents and professionals and to illustrate how each citizen can participate in the process of bringing about the kinds of significant improvements in the health and education of children with disabilities that you have so eloquently addressed over the past year. We wish you well.

— S.D.K. & M.J.S. —

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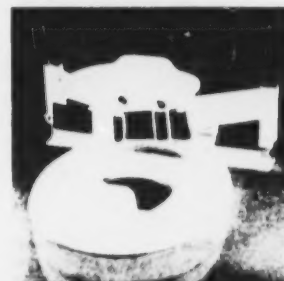
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continued from page 11

area and Jennie has had limited opportunities to meet teenagers like herself.

J.S.
Texas

Hypospadias Surgery/ Congenital Anomalies

Our 18-month-old son had a very difficult birth and was born with multiple birth defects. The umbilical cord was wrapped three times around his neck and he often stopped breathing while he was in the hospital. His chromosomal analysis and CAT scan were normal. He is not diagnosed with a syndrome.

He has a congenital heart defect (tetralogy of Fallot), cleft lip and gum, left kidney agenesis and grade four hypospadias. He was hospitalized many times during his first few months. He had open-heart surgery at 12 weeks and cleft lip repair at 16 weeks (as well as smaller medical procedures before, during and after).

Developmentally he is doing just about what an 18-month-old should, which amazes us and we count our blessings. His speech is delayed but progressing.

He faces many more surgeries in the future and I am having a difficult time dealing with this. He will soon need surgery to repair the hypospadias. I am especially struggling with this since the condition is not life-threatening but the surgery is long, complicated and can possibly affect his heart and/or his single kidney.

I have been unable to find parents of children with multiple congenital anomalies and would appreciate any response.

P.T.
Massachusetts

Looking for Friends with Similar Challenges (ABS)

We are the parents of a four-year-old girl with amniotic banding syndrome (ABS). This syndrome is caused by the fetus being constrained or compressed in its fetal habitat.

She also has borderline microcephaly and is developmentally delayed. She is an amputee who wears a prosthesis and has multiple hand anomalies. She does not speak, walk or feed herself. She is a sweet child who loves the outdoors, music, playing, etc.

We have been trying to meet parents in our area with a similar child for social activities. We are in our late 20s and she is our only child. We hoped to meet other families through support groups, retreats, etc., but we haven't met anyone in a similar situation yet and we want to find friends who have similar challenges.

We are also interested in hearing from anyone who has a child with ABS and severe or moderate retardation. ABS does not usually cause retardation unless the head is involved, so she is actually undiagnosed except for being developmentally delayed.

R.C. & D.C.
Minnesota

Cytochrome Oxidase C Deficiency

We have a 15-year-old son, Gabriel, who was diagnosed two years ago with a rare metabolic disorder called cytochrome oxidase C deficiency. Gabriel had a very normal childhood until age eight. Since then he has twice fallen into comas following stressful illnesses (flu and strep throat).

These comatose episodes were lengthy (about 30 days) and were followed by months of inpatient rehabilitation. This disorder has left my son developmentally delayed and visually impaired with strong tremors in his head and left hand, poor balance and a monotone voice.

Despite these challenges, Gabriel is doing very well. He rides the high-school bus and is included in all his classes and activities except functional academics and living skills.

We have been told that our son's disorder is very rare, usually manifests itself at birth and is degenerative. It has been four years since his last coma. Since then, Gabriel has

been taking a daily dose of 50 grams of thiamine and vitamins.

According to Gabriel's neurologist, he is stable now but there is always potential for another relapse. We are constantly worrying about the possibility of another coma that could cause more devastating brain injury.

We would like to hear from families who have a child with this disorder to correspond with them and share information and support.

M.R. & E.R.
Colorado

Absent Swallow Reflex & Chromosome Translocation

Our three-year-old son, Bryant, is developmentally delayed for a number of reasons. He was born with a translocation of chromosomes 7 and 11 and also has an apparent absent swallow reflex. Because of this major problem, he could not swallow his own saliva and would aspirate constantly, forcing him to remain on ventilatory support for two-and-a-half years.

A doctor performed a tracheal division on Bryant which stopped this constant aspiration. Now he is able to sit in an upright position and learn to do all the things he could not do when he was so ill.

We would like to talk with other parents and professionals who have dealt with translocation of chromosomes 7 and 11 or absent swallow reflex.

D.P. & C.P.
New Hampshire

Encephalocele

My son Jared was born via C-section, full-term with an encephalocele, including gross deformation in his head shape. He had a hole in the back of his skull which was five-by-five centimeters and a small dime-sized hole in the membranes surrounding the brain. His encephalocele was about the size of an orange. He had surgery when he was two days old to remove it and repair the hole. A mesh was sewn to his skull.

continued on page 18

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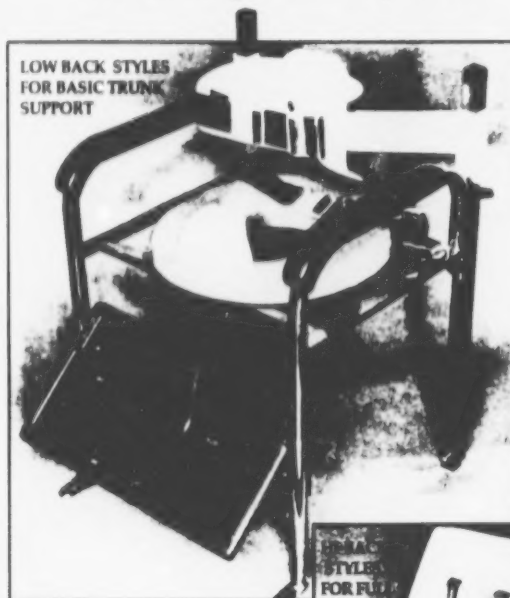


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continued from page 16

to provide resistance and help his head grow in a normal shape. At four months of age he had a VP shunt inserted to relieve mild hydrocephaly. He has had several ear infections and seems to have some hearing problems. Jared is of normal intelligence and seems to be doing very well. His head shape is good. I had no complications, took no drugs and had a good diet during my pregnancy.

I would like to correspond with someone who has a child with Jared's disability. I am particularly interested in a child with a shunt.

A.R.
Iowa

Joubert Syndrome & Trisomy 8 Mosaicism

Our 22-month-old son, Christopher, has been diagnosed with two very rare syndromes — Joubert syndrome and trisomy 8 mosaicism.

Joubert syndrome is a genetic condition in which there is a gene pair that is not working properly. This syndrome usually causes panting and apnea in the neonatal period, jerky eye movements, mental retardation, poor equilibrium and poor coordination due to the abnormal formation of the cerebellum.

Trisomy 8 mosaicism syndrome means that one of Christopher's chromosome pairs did not separate properly. This syndrome causes a prominent forehead, deep-set eyes, a prominent nose, a high palate, deep creases in the skin of the palms and soles, a long, slender trunk and mild limitation of movement in the limbs.

Christopher cannot sit up, crawl or walk without assistance, but his head control is improving every day. Christopher is currently receiving several types of therapy.

My family and I would very much like to hear from anyone with a child with either of these syndromes.

M.M.
Maryland

Developmentally Delayed

My two-and-a-half-year-old daughter, Kirstyn, was born normally after a wonderful pregnancy, labor and delivery. At seven months of age, after I noticed she wasn't doing all she should be, she was diagnosed as developmentally delayed.

She now crawls, pulls to a stand and has started side-stepping around furniture. She says no words but makes many sounds. Also, constipation has been a big problem. Feeding has gotten much easier with less frequent gagging. Kirstyn also wears leg braces (AFOs).

I would like to get in touch with any parents of similar children for support and to discuss behaviors, discipline and different ideas.

J.D.
Ohio

Herpes Encephalitis

We are the parents of a 10-month-old boy, Shane, who was diagnosed with herpes encephalitis.

continued on page 59

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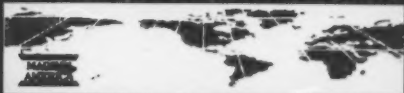
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Profound Truths

by Kathleen M. Fagley

The factors leading to our decision to place our three-year-old son in a residential facility and the ambivalent feelings we are left with even now as we celebrate his 11th birthday are central to this narrative. At the time of his placement in 1984, we found that the social service agencies and publications designed to support the families of children with multiple disabilities often did not present residential placement as a viable option. The local early intervention team and Evan's case manager felt as if they had "failed" Evan's family and ultimately Evan himself. We had to find strength within ourselves and within a small circle of friends that yes, indeed, the decision was ours to make and was a valid one considering many factors, the most important being our family's survival. Maybe other parents can make similar decisions free from guilt, blame and a sense of failure.

Evan's 11th birthday was two weeks ago, yet it is of small significance. We stopped celebrating his birthday after he turned one year old, after his weight and head circumference fell in the fifth percentile — after we realized he would never feed himself, get toilet trained or go to kindergarten. After we reached this profundity, I cancelled my subscription to *Parents Magazine*.

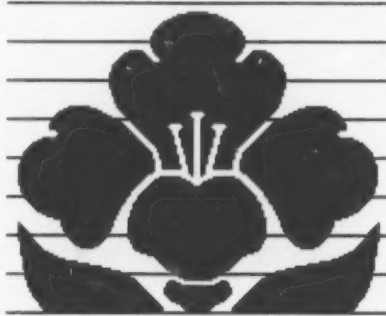
Our son was born in early April, the time of the year associated with new beginnings. I had spotted my first robin only days before, and she was as pregnant as I was. It was a glorious day, warm and sunny. I remember my daughter leaving rather hesitantly with my friend, the position of the car and the slant of the sun on our lawn. My contractions had come early in the morning as they had with my first child. It seemed like an auspicious start. But when we arrived at the hospital, our challenge began. Evan was in breech position and was reluctant to be born. The doctors were solicitous and the midwife was helpful but no amount of pushing (five hours of it, in fact) could coax our child down the birth canal.

Later we learned that this "failure to progress" was typical of infants with neurological disorders. Evan was reluctant to breast feed or move. In fact, he spent most of the next five days sleeping in the hospital nursery. Immediately after birth, his Apgar scores (evaluations of the infant's physical condition

usually made one and five minutes after birth) were normal. But after four days of sleeping, the doctor expressed concern about his lethargy and suggested further assessment. After six weeks of great difficulty getting Evan to breast feed, the doctor used another term — failure to thrive." Soon we became acquainted with many other medical terms, each one more ominous than the one before.

One of my most vivid recollections was in August 1981, when Evan was four months old. After dressing him in an abbreviated version of a sailor suit, I laid him in his playpen. When I went back to check on him a half hour later, Evan was in the same position. He had not moved from his side to his back. When I reluctantly related this story to the pediatric nurse, she wrote it down. As I told the doctor, he tried to hide his concern but he was clearly alarmed. After he left the room, I took a look at Evan's medical record. He had written "cerebral palsy." By this time I was also getting adept at reading medical files and interpreting their abbreviations and arrows. Evan's arrows all pointed down.

Within a month, we were sitting in the ophthalmologist's office talking about what we mistakenly believed was the reason Evan was not interested in my face — a strabismus, or lazy eye. The doctor mentioned congenital cataracts. Suddenly, sitting in his examining room with Evan on my lap, I asked the question I had been avoiding since the first month



after his birth. "Are congenital cataracts a soft sign of mental retardation?"

The doctor was clearly taken aback by my directness, then answered softly, "Yes."

At the Dartmouth Medical School, our initial fears were confirmed overwhelmingly. The geneticist spoke authoritatively. "Evan will never be normal. I am very pessimistic about his future." All the other doctors, therapists and interns nodded in agreement with his diagnosis.

The doctors threw around terms like cerebral palsy, microcephaly and genetic testing. I wrote everything down on a small legal pad. The act of writing somehow helped me to detach myself emotionally from the full impact of the geneticist's words. Actually, this first piece of paper was the beginning of Evan's medical, educational and legal file which today fills four large three-ring binders.

One of the doctors who had been following Evan since his first referral at three months of age let my husband, Paul, and me have a minute alone to digest the news. We stared at each other for a minute, incredulous that we had to face such a tragedy at so young an age. It was hard to talk. What was there to say?

We would be conscientious parents and do whatever we could to help Evan reach his full potential, whatever that might be. The unknown was our biggest ally at the beginning. Tears would not come that day. Only weeks later while passing out Halloween candy did I allow myself to cry. Somehow, the fact that Evan would never go trick-or-treating filled me with an insoluble sadness.

After that visit to the hospital, time took on a different significance in relation to Evan. We were not allowed the luxury to think ahead (as most parents do)

and project what our child would accomplish — his first words and steps. As I held Evan or watched him sleep, Paul and I would articulate our concerns about his flaccid muscle tone and speculate about what would happen to his body when he was five or 10 years old. But it was too painful an area to explore so we quickly retreated back to the present.

Evan was physically beautiful, endowed with large brown eyes and a lovely smile. I had enlarged one photograph of Evan. In it, he was sitting on my husband's lap wearing a white baseball cap. His cheeks were full and he was smiling, looking directly at his father's face. I had waited months for Evan to look at my face. He always seemed to be looking

somewhere beyond me, often toward the light streaming in through the windows. But in this photograph my son looked like the typical six-month-old infant. I put it in his baby book along with his lists of gifts and empty height and weight chart. Instead of the dates of the latest developmental milestone reached, this photograph would speak of my child's early days.

Immediately after birth he was a hefty 10 pounds, but within a year his muscles began to atrophy from lack of use.



"This photograph would speak of my child's early days."

If dogged determination counted for anything, Evan would have been a weightlifter by now. He was enrolled in an early intervention program. Home visitors, including a vision specialist, physical therapist, social worker and special educator, entered our home to motivate Evan and us. His limbs were put through range-of-motion exercises, his body placed on large gymnastic balls and a trail of toys were left behind. There were multi-colored Slinkys™, chickens that squeaked as they moved up and down on an elastic cord, wooden toys that rotated and sang, feather boas

continued on page 22

*The decision was ours to make and was
a valid one considering many factors,
the most important being our family's survival.*

and balls of every imaginable texture. My daughter Erin and I booby-trapped our home so Evan could not move without hitting a mobile or activating a musical toy of some sort. Unfortunately, they interested Erin more than Evan. We worked on visual tracking, timed the seconds he kept his head up and went to support groups at night to ventilate our frustrations, sorrows and joys over the challenges of parenting a child with disabilities.

While our home was being turned topsy-turvy, our daughter was fading into the background. I was busy working out all the details for equipment and camps for Evan and respite from him. This schedule would have continued indefinitely, I am sure, but within two years we had another child. That infant was not about to cooperate as well as Erin did. Erik, our youngest, was boisterous and demanding from day one. Changing two sets of diapers, a daunting task in itself, plus having a colicky infant, a toddler with disabilities and a curious preschooler was overwhelming. One day, a home visitor came to work with Evan; I looked down at my hands and noticed the remains of a diaper change embedded in my nails. I was filled with a certain loathing for the job I was required to do. When I was not changing diapers, Erin and I were searching for missing pacifiers.

One exhausting carriage trip down a country road with both Erik and Evan was the event that helped crystallize the choice I would have to make eventually. During the entire trip, which was Erik's first, I did not have time to talk to him or touch him. I was too involved in keeping Evan properly strapped in his adaptive stroller so he would not take a nose dive onto the asphalt. Evan was not the only one off-balance. The amount of time spent meeting Evan's basic needs was taking time away from two very bright, capable children and putting a strain on my marriage. With the support of my family and our pediatrician, Paul and I began to explore the option of residential placement. We decided that this process should begin before our family was in crisis and our emotional, physical and psychological resources were spent.

We began with a weekend respite at a small residential facility for children with severe disabilities located a half hour from our home. We spent time with Evan in a room filled with hospital cribs, oxygen equipment and monitors. It seemed so inappropriate, but as I laid Evan in his crib with stuffed animals and talked with the nurses and director, I reminded myself that although Evan did not have the medical problems of some of these children, he did have profound mental retardation. This facility could meet his basic needs for a weekend. From the care and concern of the staff, I was assured they could meet his other needs as well. There would be grandmothers to rock him and nurses to touch him. He would be treated with respect.

Within two months, there was an opening. Initially, it was to be a "trial" placement. Somehow the ambiguity of that term made the decision less painful. Unlike the day of his birth, the day we drove Evan to the residential facility was cold and rainy. It was Presidential Election Day, 1984. I had anticipated frequent weekend visits. Only a few of his favorite items were packed: four custom-made overalls with clouds, dinosaurs and balloon designs, and his fur piece. Evan did not travel without it. He would sit languorously in his car seat with this long, slender loop of fake fur over his shoulder — the picture of contentment.

Eight years later Evan is still at the residential facility. During the day, he is bused to a local elementary school where he is enrolled in a developmental skills program. He has begun to walk with a walker, feed himself with assistance and float in the pool at the YMCA. Just last week I watched Evan, who was terrified of water as an infant, walk down the steps into the pool with a teacher guiding him. After a few minutes of standing

calmly in the water, he pushed back gently and floated on his back, delicately using his hands to navigate. He was able to float even with his legs crossed. While he was floating, he was still smiling and gave a series of vocalizations that expressed utter delight with himself and the sensation of buoyancy he experienced in the water. I talked to him as he floated across the pool.

Again, I had to leave him. He was laughing like the day in 1984 when I laid him on his bed. He did not call for me. There were no tears this day, only happiness at the privilege of seeing this child achieve his own milestones and sharing them with people who helped in this process of growth.

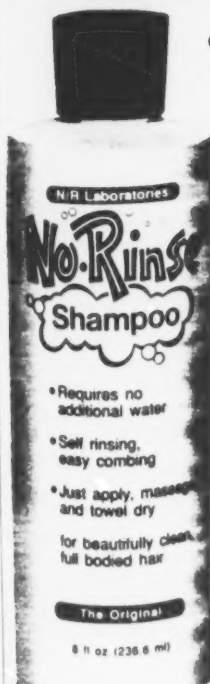
When I consider the word "profound," it describes not only Evan's education limitations but much more. As an adjective, it also describes the impact Evan has had on my life, on my husband's life. It describes his laugh and smile, his achievements and the sorrow that we feel when we realize how close he is to us geographically but how far away he is from our reach. This ambiguity, I am sure, is part of the human experience. We are left ultimately with no answers, only more questions. EP

Kathleen M. Fagley, a former teacher, is a freelance fiction writer. She lives in Keene, N.H., with her husband, Paul, and their children, Erin, 15, and Erik, 9. Their 11-year-old son, Evan, remains at the residential facility. Fagley received her B.A. in elementary and special education from St. Joseph College in West Hartford, Conn. The Fagleys are currently "actively engaged in facilitating Evan's inclusion in the Keene Middle School" to provide him with "a more diverse environment. This process has been a challenge — for us and for Evan."



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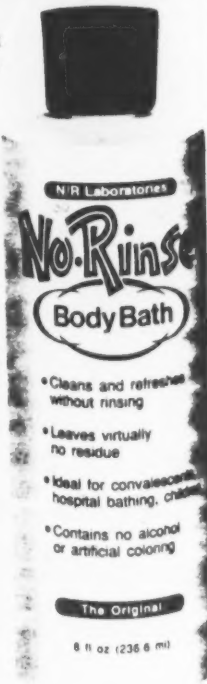
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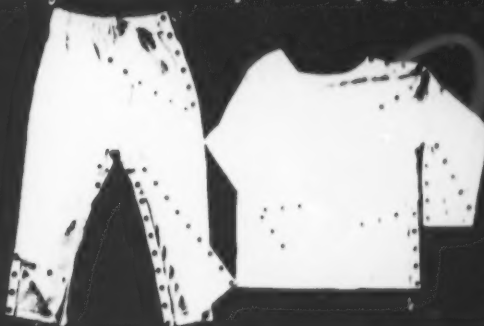
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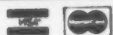
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“Why is it important for your family to have Amy in an inclusion program in her neighborhood school?” This question brought forth a flood of thoughts, memories and emotions.

As parents of two teenage daughters, Annie, 15, and Amy, 13, we can see their adulthood on the horizon. Both of them need specific training and teaching to be successful in today's world. Annie attends the local high school, where she has the abilities to find her niche in life and achieve her goals in the regular education classes. Amy has a severe communication disorder and has always needed special help.

In our community's segregated school for children with disabilities, Amy was vegetating. There were no peer role models. Expectations of the students were minimal. The student/teacher ratio was high; individual attention was not adequately provided. In that environment, we could see Amy

growing physically but not maturing emotionally, academically or socially. We knew she could do much more if she were given the right opportunity.

We have always treated Amy the same way we treat Annie, giving *both* of them responsibilities with expectations. As time slipped away, Amy became depressed, misunderstood and lost her desire to cooperate. At that low point in our lives, we learned about “inclusion.”

Inclusion

Inclusion means meeting the needs of the student with disabilities through regular education classes, with the assistance of special education. After countless hours of educating ourselves, we shared our knowledge with the local special education administration. With much prayer and deliberation, we began Amy's inclusion process last fall.

continued on page 26

**by
Nancy
Boatwright**



Amy Boatwright (seated in the center) surrounded by her Circle of Friends at school last year.

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"We found it *very* user-friendly for Jimmy's family," says Dorothy. "I just call up the night before and tell them what I want, they do the programming and it's ready for the session."

"I think the DynaVox is wonderful," says

Jimmy's mother, Ruth Ann Hess. "It's so much fun, we fight over who's going to program it. Compared to the other things out there, it's in a field by itself."

"I'm very impressed with the symbol system," Dorothy says. "You can handle the complexity of language with it. The potential is there in that device."

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Jimmy's father, Jim Hess, thinks it's exciting, too, because, "I'm actually hearing him *talk* to me for the first time."

And Jimmy agrees. "It makes me happy!" he says. "Nobody has to help me talk. I'm a big, smart boy!"

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D y n a V o x

A SENTIENT SYSTEMS TECHNOLOGY

77

continued from page 24



With the consent and support of the middle school principal, Amy was enrolled in seventh-grade regular education classes, with one class devoted to special education. Each regular education teacher modified the lessons to help Amy be a part of the class. This has been an additional challenge for these teachers, but Amy now has eight different teachers creating environments that will prepare her for the future.

When she started middle school, everything was new and exciting to Amy. She loved it and felt like a champion. It was her first "real school." She quickly began to fit in with her peers.

Circle of Friends

Many young people came forth voluntarily to befriend Amy. Through these relationships a "Circle of Friends" was developed. Thirty-four girls and boys meet with Amy and her inclusion facilitator once a week to talk about Amy's needs, her likes and dislikes and ways to continue including her in their everyday activities. These classmates have provided Amy with the friendships she has needed and wanted her entire life. She finds comfort, peer role models, acceptance and help from caring friends.

The inclusion facilitator monitors Amy's activities. She often visits Amy's classrooms and meets with the regular education teachers to help them find alternatives to fit Amy's special needs.

Because of her communication disorder, Amy does have many special needs. To communicate she uses sign language and an electronic device called an "intro-talker" to enhance her limited ability to express herself verbally.

As parents, we are part of the educational team. We provide information about Amy's strengths, weaknesses and her way of life. We often program the intro-talker to fit her needs and help make critical decisions in her educational process.

If Amy should choose to do so, we would like her to get married or share an apartment with a friend someday. We want her to be able to work alongside her peers in

the community and enjoy a full, healthy, happy life. To meet these goals she must be a part of our community's everyday life now. This will enable her to have a fulfilling and productive life later.

A New Beginning

Amy has had her challenges this first year of inclusion. She had come from a pampered, secluded school environment to the "real world." She has had much difficulty expressing herself, which is very frustrating for her. She is faced with occasional rude remarks and is having to overcome emotional immaturity.

But now, for the very first time, Amy can rely on her friends. They, in turn, have found self-worth and developed a deep

Now, for the very first time, Amy can rely on her friends.

They, in turn, have found self-worth and developed a deep sense of compassion and an appreciation of the simple, but important things in life.

sense of compassion and an appreciation of the simple, but important things in life.

Almost every day someone tells me of a heartwarming experience. Kathy and Kim, two of Amy's Circle of Friends, invited our family to attend a Christmas program at their church. Kathy's mom was the sign interpreter for the program,

which made Amy feel very comfortable. Amy was even invited to a birthday party at a friend's house this year. Because of experiences like these, Amy now talks more, walks better and wants to be like her teenage friends. All of this would not have been possible without the caring skill the inclusion facilitator provides each day, along with the willing creative ability of her regular education teachers.

Our family can see a brighter future on the horizon. We have peace of mind knowing we are on the right path with inclusion. It is not the path of least resistance — it's a new beginning! EP

Nancy Boatwright lives in Tyler, Texas, with her husband, Cecil, and daughters Annie and Amy, now 16 and 14. She is a homemaker, freelance writer and a parent assistant specialist with Partners Assisting Texans with Handicaps (PATH). She is also a public speaker in Texas on Circle of Friends and inclusion. "We are true believers in *Exceptional Parent* magazine. It led us to the right people to get inclusion started here in Tyler."



Amy shows off her intro-talker and her Circle of Friends group photo (top); Amy poses with her sister Annie (middle); and a Boatwright family portrait taken on vacation last summer (above).



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Setting a Precedent

by Edwin Martin

Edwin Martin, Ph.D. is president and chief executive officer of the National Center for Disability Services in Albertson, N.Y. The center, which was established 40 years ago, provides educational and vocational research and rehabilitation programs for adults and children with disabilities.

My wife, Peggy, tells a story about our early years in Washington, D.C., while I was on leave from a university faculty working as staff director for the House of Representatives Subcommittee on the Handicapped. It is about a conversation I don't remember. One night during dinner I expressed my happiness about Congress passing a piece of legislation I had helped draft, and I said, "We did something today that is going to help one million children with disabilities."

She said later that she knew at that time that we would not soon be returning to the campus, and she was right. I had learned that I could use my professional training to affect public policy and hopefully help many children.

The act she referred to was the first "Education of the Handicapped Act" in 1966, which for the first time began to provide federal funds to the states for the "initiation, improvement or expansion" of programs to educate children with disabilities. As significant as that legislation was (it also created a top-level federal agency — the Bureau of Education for the Handicapped, BEH), there was an even more significant event still to come.

By 1972, I had the privilege of serving as Deputy Commissioner of Education and Director of the BEH, a part of the U.S. Office of Education in the Department of Health, Education and Welfare. The BEH played a leadership role in developing federal policy affecting education of children with disabilities. It was also responsible for administering federal programs which helped train teachers, assist states and local school districts with support for programming and provide funds for research, demonstration and the development of new and better ways to educate children with disabilities.

The year 1972 found me immersed in a campaign to create a policy that would correct a terrible wrong. Across the nation, parents found their children with disabilities being turned away from schools, inappropriately served or attending schools but not receiving special education assistance.

Only a relatively few children with disabilities, estimated at one or two out of five, were in special education classes or programs. No state was serving all its children with disabilities, and even in the

few states that had "mandatory" laws requiring such programming, there were either exemptions permitted or the laws were not fully implemented or enforced.

In the winter of 1969, as President Nixon planned to take office, I joined with Fred Weintraub of the Council for Exceptional Children (CEC) in urging the Nixon "transition team" to make a commitment to children with disabilities a part of their administration. We pushed that agenda again with the President's Bureau of the Budget, but ultimately the administration decided that the burden of financing school services should be on the states and the federal role should be limited to such activities as research and teacher education grants.

When a new education commissioner joined the Nixon administration in 1971, I urged him to make education of children with disabilities one of his major priorities. Sidney P. Marland agreed, and once again we approached the Bureau of the Budget, but with no greater success.

We decided to change our wording, and instead of declaring it a national goal, we "called for the development of a national goal of educating all handicapped children by 1980." To implement that goal, we stimulated grass-roots activities, making a film of Commissioner Marland urging such a goal and circulating it to every state education agency.

In addition, I worked with various groups to adopt the goal, chief among them the CEC, our partner for all practical purposes, and the Education Commission of the States (ECS). The ECS is an organization involving governors, state legislators and state school board officials. The CEC developed a model state law and we introduced it to state legislators through ECS conferences. Bit by bit, laws were strengthened in virtually every state.

Meanwhile in Washington, a significant event had occurred. Lisa Walker, a political scientist working as a staff assistant to Sen. Harrison Williams, called to tell me that Sen. Williams, then Chairman of the Senate Labor and Public Welfare Committee, had agreed to name a special subcommittee on people with disabilities and sponsor major legislation. She was looking for good ideas.

In the House of Representatives, Rep.

HALL OF FAME

John Brademas expressed a similar interest and his counsel, Jack Duncan, began meeting with Lisa, Fred Weintraub and me. As we progressed, many other organizations and individuals became involved. We began drafting what was to become a major national law and a model for other nations.

A very significant event occurred in 1971 when a federal district court in Pennsylvania issued what is called a consent decree, an agreement between plaintiff and defendant to certain conditions which resolve a lawsuit. In this case, the issue was whether or not Pennsylvania could deny educational opportunities to children with mental retardation.

This landmark case, often called the PARC (Pennsylvania Association of Retarded Children) case, indicated that federal courts were seeing educational opportunity as something akin to a constitutional right. At

least education could not be provided on a discriminatory basis. The following year, another federal court, this time in the District of Columbia, expanded the ruling to cover children with all kinds of disabilities, not just mental retardation.

In a very real sense, the pieces in the puzzle were fitting together — a documented need, action at the state level which created a need for more funds, federal and state courts pushing for equal treatment under the law and legislation pending in Congress which would greatly increase funding to the local school districts and protect the rights of children with disabilities and their parents.

The Bureau of Education for the Handicapped (BEH) provided a central government agency for coordinating efforts and supplying information, resources and considerable advocacy, despite the continuing

reluctance of the Nixon and Ford administrations to commit major federal funds to the effort. As director of the BEH, I was able to work effectively with congressional staff members and with parents and professionals to advance the legislation.

In 1975, the Education of All Handicapped Children Act was passed and acknowledged by advocates and detractors to be the most far-reaching education/consumer rights legislation ever to be passed by Congress. Today more than 4.6 million children benefit from its provisions and Congress appropriates more than \$2 billion annually to assist in educating those children.

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Coping with Incontinence

by Katherine F. Jeter

Toilet training is an important milestone in human development and in Western culture. In our society we attach social value to bladder control. Likewise, shame and embarrassment are often associated with failure to achieve bladder control or loss of bladder control with injury or illness. Gaining bowel and bladder control under even the best circumstances is an amazing feat. There are so many factors that affect the bladder's ability to store and release urine. Let's look at that process.

The kidneys filter waste from the blood. This becomes urine. The urine is moved from the kidneys to the bladder by a gentle squeezing motion called peristalsis. The bladder is a sac-like muscle. As the bladder fills and stretches, it sends a message to the brain via the spinal cord that it is filling and needs to be emptied when it is convenient.

The brain then sends a message back to the bladder that it is or is not the proper time and place to be emptied. When the bladder is emptied, the bladder outlet muscle, called the sphincter muscle, relaxes and opens so the bladder can contract to squeeze urine out. The urine flows from the bladder through a small tube called the urethra to the outside of the body.

Children with mental and physical disabilities may have disturbances in some body systems that control bowel and bladder function. They may not feel the bladder getting full; they may not be able to control the sphincter muscle; they may not be able to understand where or when it is proper to urinate or have a bowel movement.

Urinary incontinence, the medical term for lack of bladder control, is a symptom. It is not a disease. If your child does not achieve urinary continence between the ages of three and five, you should talk to your pediatrician. He or she will probably refer you to a urologist, who will perform tests of the bladder and bladder outlet muscle.

Pediatric urologists have special interest and training in the kidney and bladder problems of children. A pediatric urologist will probably be most helpful in your search for the cause and best treatment for your child's incontinence. The following helpful hints will not interfere with your doctor's treatment and may improve your child's bladder control. At the very least, these suggestions should reduce the family tension that often arises when bladder control is not achieved "on time" or is lost after illness or injury.

Encourage bladder control. Don't punish.

As you have just read, many anatomical (how the body is made), physiological (how the body works),

neurological (how nerve messages are delivered in the body) and psychological (how the mind reacts to internal and external messages) factors are involved in achieving bladder control. Daytime bladder control is usually achieved between two and three years of age. Control at night often comes later. If your child has mental or physical limitations, urine control may be delayed for months or even years.

Your child will not understand the inflated value we put on toilet training or the annoyance and nuisance of extra loads of laundry required when bed linens and clothing have been saturated. Separate the physical fact of your child's urine leakage from the psychological and emotional effect the incontinence has on you and your family. Be patient and encouraging. Punishment will not promote continence.

Watch your child's fluid intake.

There are certain beverages children love that may interfere with day and night bladder control. Among the most offensive drinks are caffeinated and carbonated beverages, such as the colas many parents use as special treats.

In addition, coffee, tea and milk may cause problems when it comes to bladder control. Some people have noted that drinks sweetened with artificial sweetener are linked to their children's bladder leakage. Encourage water, pear and apricot nectar and cranberry and cherry juice. Citrus fruits and juices (grapefruit and orange are the most common) should be offered in very small amounts, if at all.

Many children and their concerned parents will limit fluids thinking that less fluid in means less urine leaking out. Actually, your child should be given enough fluids so the urine is colorless and has no odor. Dark, foul-smelling urine is a sign of urine infection or highly concentrated urine. Highly concentrated urine is irritating to the bladder, making the bladder want to get rid of it quickly. Make fluids available in reasonable amounts. Do not use fluids as rewards or punishment to improve bladder control.

Chocolate is also full of caffeine and can be a potent bladder irritant. Try canned or fresh fruits as a substitute to satisfy a craving for something sweet.

Make the toilet safe and comfortable.

The toilet your child uses should have a seat that fits. Many children are frightened when they cannot sit securely on the commode without fear of falling in. This

continued on page 32

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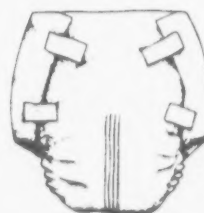


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fear may cause their abdominal muscles and bladder outlet muscles to tighten, which can interfere with urination. Feet should rest comfortably on the floor or on a stool. Do not encourage grunting, straining or pushing. Remember, the sphincter muscle must be relaxed for the bladder muscle to squeeze and empty.

You may want to run water, put your child's hand in warm water or pour warm water between the legs to encourage urination. Other techniques people use to encourage the bladder to empty are stroking the inner thighs or tapping lightly over the bladder which is located between the belly button and the pubic bone.

Praise is in order when your child passes urine or has a bowel movement on the toilet. Punishment or ugly words are never in order when your child does not "have results."

Protect the skin and self-esteem with the best incontinence products.

There are special cleansers, moisturizers, moisture barrier creams and ointments to keep your child's skin in good condition. As children get older, their urine and stool may become more irritating to the skin. When children are trying to be independent, you can help them care for themselves.

For instance, a squeeze bottle, such as you might put ketchup in, can be used with a rinseless skin wash. Your youngster can squirt the cleanser while sitting on the toilet and blot dry before getting off the toilet. Easy-to-reach continence products and a receptacle to put soiled or used disposable garments will make it easier for your child to tidy up.

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Help your child find a comfortable, absorbent system that keeps the ego intact and the urine absorbed. Do not use diapers as punishment for daytime incontinence or bedwetting.

Be reasonable about nighttime control.

Children with developmental delays may be very late in achieving nighttime continence. Some may never have complete and predictable control at night. If this is your situation, find a garment or padding system that allows your child to sleep comfortably while protecting the bed linens and mattress.

Learn all you can about how to promote continence at night. *Waking Up Dry* is a book by psychologist Dr. Martin Scharf. He wet his bed as a child so he knows firsthand how upsetting that can be. This book is good for children of all ages and their parents. It will give you everything you need to encourage continence at night if your child's mental and physical condition permits it.

Be an informed and understanding advocate.

Do not let urinary or fecal incontinence limit your child's development or cause family arguments or neighborhood ridicule. Sometimes arms and legs don't work right, words don't come out correctly or eyes don't focus correctly. Sometimes the bladder doesn't work right either; it doesn't fill and empty as we wish it would. This is simply another organ system that can be affected by birth injury, illness or accident. It is not the measure of intelligence or social worth that our society falsely attaches to this system's function or malfunction.

Katherine F. Jeter, Ed.D., E.T., is the founder and executive director of Help for Incontinent People, Inc. (HIP), a nonprofit advocacy organization whose mission is to improve the quality of life for people with incontinence.

Jeter has written more than 150 scientific papers and numerous chapters on the subject of ostomies, incontinence and wound management. She lives in Spartanburg, S.C., with her husband, Col. (Ret.) John R. Jeter, Jr. The couple has three children and three grandchildren.

Help for Incontinent People

Help for Incontinent People, Inc. (HIP) is the leading source of education, advocacy and support to the public and the health profession about the causes, prevention, diagnosis, treatments and management alternatives for incontinence. For 10 years, HIP has helped children and adults improve bladder control when possible and manage lack of bladder control safely and comfortably when continence is not possible.

HIP also publishes *The HIP Report*, a quarterly newsletter full of information about the latest treatments for incontinence and helpful hints from readers who have found solutions for their condition. The *Resource Guide of Continence Products and Services* is a 72-page catalog listing every type of incontinence garment and device with line drawings to show you what each item looks like.

HIP has a variety of educational leaflets and books available, including *Waking Up Dry*. HIP membership is \$15 per year, which includes a current resource guide and four issues of *The HIP Report*. The resource guide can be purchased for \$10 and *Waking Up Dry* is \$10.95, postage paid.

For more information about the support services offered by HIP, send a self-addressed, stamped, business-sized envelope to HIP, Box 544, Union, S.C. 29379. An optional \$1 contribution would be appreciated. Materials can also be ordered by calling (800) BLADDER.

The **Simon Foundation for Continence** is committed to increasing public awareness of incontinence, removing the social stigma attached to this disability and educating those who have incontinence, their families and the professionals responsible for their care.

For more information, contact the Simon Foundation for Continence, P.O. Box 835, Wilmette, Ill. 60091, (708) 864-3913, (800) 23SIMON.

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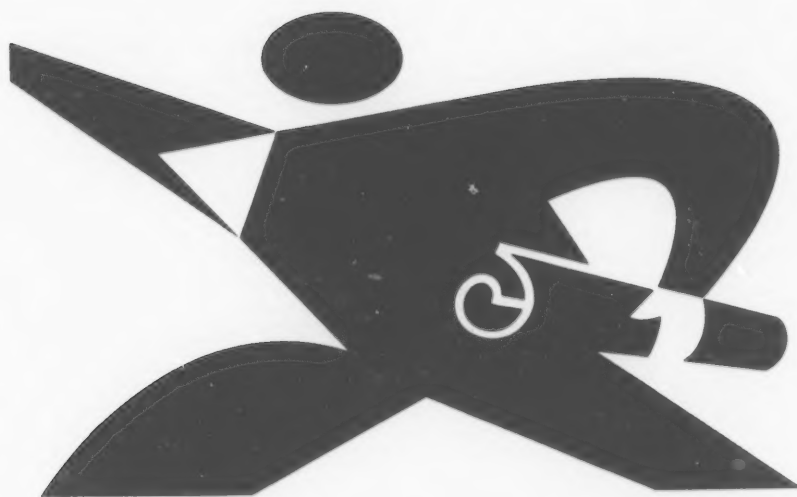
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24/31

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Coup in progress...

On January 5, 1993 Apple Computer, Inc. began a revolution. Coup de Tech. It's a welcome, of sorts, to the 21st Century. And a kick in the pants to business as usual. Since that day, individuals from around the world have come together to change what it means for a child or an adult to experience a disability.



revolutionaries welcome.

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School Mainstreaming Contest Winners, 1992

This issue we are proud to honor one outstanding middle school program and commend two other school programs to close out our 1992 mainstreaming contest. We look forward to another record number of entries this year.



SOUTHWEST MIDDLE SCHOOL ORLANDO, FLORIDA

Students with physical disabilities at Southwest Middle School are placed into at least two appropriate inclusion/mainstream classes, regardless of academic level. Most are fully mainstreamed. When necessary, a teacher's aide accompanies students who use augmentative communication aids and special access equipment. Other students take notes for some of the students with

disabilities on NCR paper. All students with and without disabilities eat lunch together and mix in a natural way.

The positive results achieved at Southwest are the product of the open-minded, flexible attitudes of the principal, regular education teachers and counselors. The creative use of computers in the classrooms enhances the motivation and academic achievement of the students, especially those with disabilities.

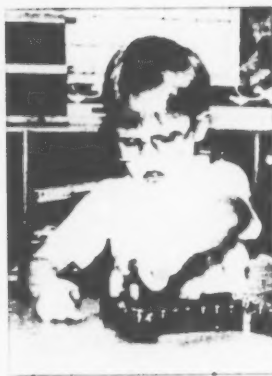
Contact: Pat Hackett-Waters, Physically Impaired Unit Liason, Southwest Middle School, 6450 Dr. Phillips Blvd., Orlando, FL 32819, (407) 363-9760, (407) 352-6911.



Seventh grader Faye Warren with fellow ghouls on Halloween (above), relaxing after school with classmate Ben (left) and having fun at Kid's Village in Quest class (right).



COMMENDATIONS



A young boy works on a string art masterpiece (left), three Benson Memorial students listen to tapes in music class (above left), a little girl plays in the sandbox (above right) and a preschooler learns all about Mexican sombreros (right).

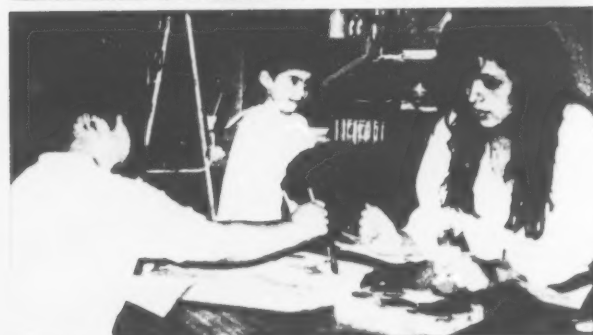
BENSON MEMORIAL PRESCHOOL RALEIGH, NORTH CAROLINA

Benson Memorial United Methodist Weekday Programs is a preschool serving 138 children from the ages of three to five. The program provides a range of classroom opportunities, including a component to serve children with special needs. In five years, the special-needs program has grown from a three-day class serving five children to a five-day program serving 11 children, in addition to those children

with special needs who are fully integrated in regular classes. Many of the children who enter Benson as members of the special-needs class are now being served at Benson through the public school system as mandated by legislation.

Each class attends music class twice a week and this year students will be offered a movement component. Both of these opportunities help provide positive and adaptable mainstreaming opportunities for all of the children at Benson.

Contact: Susan Jarrell, Director, Benson Memorial Preschool, 4706 Creedmoor Rd., Raleigh, NC 27612, (919) 781-3310.



PASADENA UNIFIED SCHOOL DISTRICT PASADENA, CALIFORNIA

Pasadena Unified School's inclusion model incorporates team teaching to provide opportunities and support to children with special needs in a regular classroom. Approximately one-fourth to one-third of the children in each classroom have identified special needs.

Next year, eight to 10 classrooms will be offering this inclusion/team-teaching option for students. Classes will include preschool, kindergarten and first grade. Students with special needs will range in age from three to nine.

Contact: Suzi Hoge, Pasadena Unified School District, Children's Services, 351 South Hudson Ave., Pasadena, CA 91109, (818) 795-6981.

A student receives computer help from his teacher (top left), while two special-needs students work on paintings in art class (bottom left).

Annual Income Tax Guide

That time of year is upon us once again — the 1992 tax season. Just the thought of filing those intimidating returns strikes fear into the hearts of many parents. Tax forms are difficult enough for the average family, but for parents of a child with a disability, the process can be even more frustrating and time consuming. This article will help guide you through the often confusing maze of new legislation, tax rules and tax credits.

What does this mean to you, the panicked parent? Relax. There were not many new rulings this year on disability issues, so there are few changes to worry about.

Medical Deductions

The first thing to determine is whether or not it is worthwhile for you to claim medical deductions. Medical expenditures are only deductible if they total more than 7.5 percent of your adjusted gross income. In other words, if your medical expenses total less than 7.5 percent of your income, it is unnecessary to file medical deductions.

If your income is low enough that little tax is paid on it, however, there is no need to file medical deductions as a means of saving taxes. Be sure to reduce your medical expenses by the total reimbursements you have received, including insurance compensation and payments made directly to doctors and hospitals.

Claiming medical deductions requires a considerable amount of effort and organization. The IRS processes tax returns by a computer that automatically singles out a taxpayer with high deductions. Since parents of a child with a disability generally fall into this category, they have a greater risk of being audited. Proper documentation is necessary, so keep receipts, prescriptions and any other expense records related to your child's disability.

Besides assisting you in the event of an audit, organized records will help you fill out your return

correctly. It is important to remember that the IRS can audit your tax return for up to seven years after the return is filed, so keep records from the last seven years in a safe place.

One way to reduce the chance of a future audit is to enclose a letter with your return explaining your child's disability and another letter from your child's physician describing the nature of the disability and the prescribed care.

Many medical expenses may not be deductible or covered by insurance, but there are some deductible expenses you may not have thought to take. This article

will discuss a few of the allowable medical deductions. For a complete, detailed list, see IRS publication #502, *Medical and Dental Expenses*. The law provides a limited deduction for the following expenditures under the category of "medical care":

- Prescription drugs and insulin.
- Medical insurance premiums and certain medical transportation costs, such as bus or taxi fares or car/gas expenses (at a rate of 9¢ per mile) to receive care.
- Lodging for a person receiving medical care away from home (and for an accompanying parent or guardian if the person receiving care is unable to travel alone), limited to \$50 per person per day, plus the cost of meals, as long as they are furnished by a

hospital or similar institution.

- Modifying a vehicle with a wheelchair lift.
- Adapting a home to the needs of a child with a disability, such as installing hand railings, support bars and entrance and exit ramps; modifying a bathroom; widening doorways or hallways; adjusting kitchen cabinets, electrical outlets, fixtures, stairs and hardware on doors; installing lifts; and grading the ground in order to provide access to the home.

These modifications are fully deductible because they do not increase the value of the home. Other "medically necessary" adaptations, such as the installation of

continued on page 40



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CONFERENCES

Franciscan Children's Hospital

30 Warren Street
Boston, MA 02135-3680
(617) 254-3800, ext. 1510
"Caring for Children with Disabilities: Challenges in Rehabilitation" to be held March 26, 1993, at the Vista Hotel in Waltham, MA. Call for more info.

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Advertiser	Page #	Advertiser	Page #
Ability Research	13	Imaginar	33
Anne Carlson	65	Innocomp	5
Apple	34, 35	Innovative Products	23
Berkshire	63	Institute of Logopedics	59
Bethesda Lutheran	62	Jay Medical	1
Bissell-JA Preston	back cover	Jesana Ltd.	11
Braun	19	Kid-Kart	5
Bruno	9	Laureate Learning	43
Cardinal Cushing	61	League School	61
Charles C Thomas	53	Martha Lloyd	61
Chrysler P-Cap	10	Medical Innovations	6, 7
Columbia Medical	15, 17	Mobile-Tech	13
Cotting School	58	Mobility Tech. Corp.	13
Crystal Springs	64	N/R Labs	23
Developmental School	64	Nesheeka	23
Devereux	67	New Breakthroughs	17
DRI Pride	31	New England Villages	62
EP Back Issues Ad	43	Pathfinder	64
EP Book Ad (Lash)	43	Phonic Ear	18
EP Subscription Strip	33	Prentke Romich	17
Equipment Shop	29	Quickie Designs	inside front cover
Estate Planning	12	Sentient Systems	25
Flaghouse	15	Snug Seat	2
Gillette Children's Hospital	27	St. Coletta School	58
HDIS	33	Stewart Home	63
HMS School	64	TASH	inside back cover
Macienda de los Angeles	63	Toys for Special Children	29
Hoening Mobility	33	Woodbury Products	15, 31

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an elevator, swimming pool, air filter, humidifier or air conditioner, may increase property value. If they do, you can only deduct the difference between the cost of the improvements and the property value increase. You should also secure a doctor's prescription to support the deduction for these medical expenses. Maintenance, repair and electricity costs for these modifications are deductible as well.

If paying for expenses by check or a "pay-by-phone" method, the deduction is made in the year in which the payment is made. If paying by credit card, expenses are deductible in the year that the charge is made, regardless of when that charge is actually paid. Therefore, keep all canceled checks, bills and receipts related to deductible expenses. Any expenditures reimbursed by insurance during the calendar year are not deductible.

Special Education and Training

If your child attends a special school because it offers resources which alleviate his or her condition, tests, evaluations and training such as lip reading, speech or Braille instruction are all deductible medical expenses. If your child attends a school specifically because it provides medical care, full tuition costs are deductible. However, if the school offers medical care but your child is enrolled for other reasons, only the expenses directly attributable to medical care are deductible.

A deduction is also available for parents who, in the event of their deaths or inability to care for their child, pay nonrefundable advance payments to an institution for the future acceptance of their child with a disability. Those deductions are allowed in the year the advance is paid.

Other Tax-Deductible Expenses

Although the law provides a limited deduction for the expenditures listed above, parents should be aware of other deductible expenses that may relate to their child's disability:

- Rehabilitative toys, playthings and special equipment such as Braille books and magazines.
- Orthopedic shoes or an extra pair of shoes because of different foot sizes.
- A hospital bed, special mattress, plywood headboard or elastic support stockings.
- A service that uses computers to store personal medical information, a TTD machine, a computerized visual alert system or a television set or adapter that enables a child with a hearing impairment to understand closed-captioned programming.
- Cost and care of guide dogs.
- Disposable diapers for children with incontinence.
- Doctor-recommended therapy, such as music lessons.

Tax Credits

Certain income tax credits provide more ways to reimburse the costs associated with the care of a child

with disabilities. The cash benefit of tax credits equals the actual credited amount and does not depend on an individual's tax bracket as tax deductions do.

- The *Child and Dependent Care* credit is available for certain parents. If you pay someone to care for your child while you work, seek employment or attend school full time, you may be entitled to a tax credit of up to 30 percent of the amount paid for the care. You can claim a credit for expenses up to \$2,400 for one child or \$4,800 for two or more children. See IRS publication #503, *Child and Dependent Care Expenses*.

- The *Earned Income Credit (EIC)* is a special credit for workers whose annual income is less than \$22,370 and who have a child or children living with them at least six months out of the year. It reduces the amount of taxes owed and offsets increased living expenses and social security taxes. You can subtract your EIC from the taxes you owe or get a refund, even if you did not have tax withheld from your pay. To receive the credit, you must fill out Schedule EIC and enclose it with your tax return. The EIC consists of three credits:

The **basic credit** you can take depends upon the number of qualifying children living with you. To qualify, your child must live with you for more than half the year and your main home must be in the United States. Also, you must either be married and filing a joint return, a qualifying widow(er) with a dependent child or the head of a household. You may be entitled to a credit of up to \$1,324 if you have one qualifying child living with you and up to a \$1,384 credit if you have two or more qualifying children in your household.

The **Health Insurance Credit** may be taken in addition to the basic credit. If you paid health insurance premiums that include coverage of the qualifying child(ren), you can take credit of as much as \$451. If you claim the health insurance credit, you must deduct it from other medical expenses claimed.

The **Extra Credit for Newborns** is limited to one qualifying child under the age of one on Dec. 31, 1992, and can be as much as \$376. If you take this credit, you cannot claim the credit for child and dependent care expenses. If you are eligible to claim both credits for the same child, you must choose only one. Choose the credit that will give you either the lowest tax or the largest refund. If you do not owe any tax and did not receive any employer-provided dependent care benefits, you should claim the extra credit for a child born in 1992 to receive the largest refund.

If you are not required to file a tax return because your income is below the minimum for filing, you can still receive the EIC if you wish to file for it. The IRS will figure out both your tax and your EIC on form 1040 or 1040A. For more information, see IRS publication #596, *Earned Income Credit*.

If you claim your child as a dependent on your tax return, your child cannot claim a personal exemption on his or her own return, even if your child is a full-time student and worked over the summer. Your child can,

continued on page 62

PRODUCT SHOWCASE



Top Drawers

Top Drawers offers the finest reusable products for the incontinent child and adult. Featuring all-cotton diapers (as shown), colorful nylon waterproof covers and related accessories. The bright colors will lift your child's spirits while offering the comfort of soft fabric, so much nicer than paper and plastic. Free catalog available. Call or write for details.

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On the Ice

by Mary Greenlaw

Parents are not permitted to step gingerly into the world of children with developmental disabilities. Rather, we are cruelly shoved from behind and, like novice skaters, we must fight to maintain our balance in a situation which may never be quite balanced. I believe my view will ring true for many parents who find themselves desperately seeking answers to questions for which the professionals have no answers. When will our child walk? Will he be diagnosed? What will the future hold for him and our family? Everything we thought would come in an orderly, natural fashion is now closely scrutinized. As for the answers, we can only wait and see. We are plagued by our fears. Do we have too many expectations? Or too few?

When my child stepped off the expected route and pushed me onto the ice, I became obsessed with my quest for answers. Like a hunter, I chased down every clue and examined all the evidence. Instead of answers, I discovered only more questions and doubts. Like a novice skater, I lurched about wildly, trying to steady myself, while all around me others seemed to skate by effortlessly. Reading became my all-consuming hobby. Not romance novels or adventures, mind you, but case histories and medical journals. I tried to achieve my balance through reading, research and the constant lists that made up my day. Listing our days, our nights, our dreams and our hopes

became my life. Reality seemed anchored in those lists — tangible proof of life.

I've grown accustomed to the ice now. Finally, with the passage of time, that all-powerful healer, I can think of other things. My journals, once daily proof of my existence, are no longer daily-kept records of my son's achievements and unmet goals. My balance, precarious as it may be, is born of my

acceptance — but not of my son's condition. To accept that would mean to let go of all my hopes and expectations, the dreams that make up life itself. My acceptance is of my son as the individual he is and will become.

Ultimately my acceptance is for me. I can now accept all the emotions that at one time threatened to crush me under the ice. Feeling everything and, at times, feeling nothing, I pick up the pieces of my

life and find myself out on the ice. With the hand of a small boy in mine, I move among the skaters, not exactly gliding but steady, my balance maintained by his constant presence. *EP*

Mary Greenlaw, an art teacher, lives in Simsbury, Conn., with her husband, Mark, and her three children, Shawn, 14, Carrie, 10, and Ryan, 7. She is a teaching assistant at King Phillip Middle School in West Hartford, Conn., and taught art at the Simsbury Music and Arts Center last summer. Greenlaw received her bachelor's degree in art education from Central Connecticut State University in New Britain, Conn.



My balance, precarious as it may be, is born of my acceptance of my son as the individual he is and will become.

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	Nov/Dec 1991	9th Annual Computer Technology Issue; Parenting Your Child Without Disabilities.	
	Oct/Nov 1991	Is Your Child Being Humiliated? Car Seat Safety; Tips for Parents; 800# Directory.	
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RESOURCE SECTION

(800) Numbers



The following telephone numbers are national toll-free numbers of organizations that provide assistance to people with disabilities and their families. The listings range from general information and useful hotlines to specific topics.

Adoption

National Adoption Center
(800) TO-ADOPT

Americans with Disabilities Act

Disability Rights Education
Defense Fund
(800) 466-4232
(Voice/TDD)

Equal Employment
Opportunities Commission
(800) USA-EEOC
(800) 800-3302
(202) 663-4494

Office of Fair Housing and
Equal Opportunity
(800) 424-8590
(202) 708-4252 (in DC)

U. S. Architectural
Transportation Barriers
Compliance Board
(800) USA-ABLE

Career Counseling

ERIC Clearinghouse
on Adult Career and
Vocational Education
(800) 848-4815

Higher Education and Adult
Training of People
with Disabilities
HEATH Resource Center
(800) 54-HEATH

Job Accommodation
Network
(JAN)
(800) 526-7234
(800) 526-4698 (in WV)
(800) 526-2262 (in Canada)
(800) DIAL JAN (Bulletin
board phone lines;
Voice/TDD)

Job Opportunities
for the Blind
(JOB)
c/o National Federation
for the Blind
(800) 638-7518

National Clearinghouse on
Postsecondary Education
for Individuals w/Disabilities
(800) 533-9673
(800) 321-8337 (TDD)
(703) 998-2400

Computers

Apple Computers
(800) 732-3131 (Catalogs)

AT&T Computers
(800) 247-1212

IBM National Support
Center for Persons
with Disabilities
(800) IBM-2133

Education

National Committee
for Citizens in Education
(800) NETWORK

Financial Aid

Federal Hill-Burton
Free Care Program
(800) 638-0742

Medigap Information
c/o Health Care Financing
Administration
(800) 638-6833
(800) 492-6603 (in MD)

General Information

National Center for Youth
with Disabilities
(800) 333-6293
(612) 626-2825

National Information
System and Clearinghouse
(800) 922-9234
(800) 922-1107 (in SC)

Government Agencies

Consumer Product Safety
Commission
(800) 638-2772

HUD Housing
Discrimination Hotline
(800) 669-9777
(202) 426-3500 (in DC)

National Information Center
for Children and Youth
with Disabilities
(NICHCY)
(800) 999-5599

Health Information

Children's Hospice
International
(800) 24-CHILD

National Health
Information Center
c/o Office of Disease
Prevention and Health
Promotion
(800) 336-4797

National Information
Systems for Health Related
Services
(800) 922-9234

National Organization
on Disability
(800) 248-ABLE

Office of Minority Health
Resource Center
(800) 444-6472

Hotlines

District Internal Revenue
Service —
Tax Information
(800) 829-1040
(800) 829-3676 (Forms)

National Spinal Cord Injury
Hotline
(800) 526-3456

SSA Hotline
(Social Security
Administration)
(800) 772-1213
(800) 325-0778 (TDD)

TDD and TTY Operator
Services
(800) 855-1155
(202) 708-9300 (in DC)

Media Resources

Handicapped Media
(800) 321-8708

National Captioning
Institute
(800) 533-9673
(800) 321-8337 (TDD)
(703) 998-2400

National Library Service for
the Blind and Physically
Handicapped
(800) 424-8567
(202) 707-5100

Medical Devices

Practitioners' Reporting
System
(800) 638-6725
(301) 881-0256 (in MD)

Professional Organizations

Academy of Dentistry
for the Handicapped
(800) 621-8099, ext. 2660

American Federation
of Teachers
(800) 238-1133

National Association
of Social Workers
(800) 638-8799

Rare Disorders

National Information Center
for Orphan Drugs and Rare
Diseases (NICODARD)
(800) 456-3505

National Organization
for Rare Disorders (NORD)
(800) 999-NORD

Rehabilitation

National Rehabilitation
Information Center
(800) 34-NARIC
(Voice/TDD)

Second Opinions — Surgery

National Second Surgical
Opinion Program
c/o Health Care Financing
Administration
(800) 638-6833

Telephone Usage for Persons with Disabilities

AT&T National Special
Needs Center
(800) 233-1222
(800) 833-3232 (TDD)

Tele-Consumer Hotline
(800) 332-1124
(Voice/TDD)
(800) 223-4371
(Voice/TDD, in DC)
Also in Spanish

U. S. Government
TDD Directory
Federal Information
Relay Service (FIRS)
(800) 877-8339
(202) 708-9300 (in DC)

Travel

National Tour Association
Handicapped Travel
Division
(800) NTA-8886

WE RECENTLY INVITED ALLIANCE FOR TECHNOLOGY Access centers to submit success stories describing individuals or families who have incorporated technology into their lives. Starting with this issue, *Exceptional Parent* will publish these stories.

In many cases, specific products illustrate the wide variety of technology tools available and represent a few of the many products demonstrated and used at ATA centers.

ATA Scrapbook of Success

A Future Brightens

"I want to be a writer." These are the words of 10-year-old Kristen who is in a regular fourth-grade class in Thousand Oaks, Calif., and a member of the ATA center in Simi Valley, Calif.

Kristen is very similar to the other children in her class. She loves to go to the movies, talk to friends on the phone, have sleep-over parties and play dress up. She also loves to write on her computer and create stories to share with her friends and relatives. She now has more than four notebooks of her stories and many are about Kristen, the upside-down fairy who sees everything in her world just a little bit cockeyed.

Kristen will never write with a pencil as she has difficulty even grasping a piece of paper. She has cerebral palsy and drives her motorized wheelchair with a joystick.

She has use of only one hand and needs to be supported to sit up in her wheelchair. The computer is her pencil and paper. When she types on the computer, she uses a plastic Key-guard which stabilizes her hand and enables her to hit one key at a time.

The computer Kristen uses in school has allowed her to be an active participant. The school has assigned an aide to assist her, but Kristen profits most by doing her own work. Three years ago the term "attention deficit" was used in reference to Kristen, but that may have been because Kristen had to depend

upon and wait for an aide to write her answers. Now Kristen is doing her own writing and her ability to stay on task is very appropriate.

She learned to spell by using a program called *Magic Spells* that flashes a word on the screen for six seconds and then asks Kristen to spell it. This program allowed her to learn to look at the whole word rather than one letter at a time, which helped develop her spelling skills.

Writing is her biggest joy and many afternoons she will wheel up to her computer and write poems and thoughts she wants to share. Graphic software like the *Children's*



Kristen uses her computer to share stories with relatives and friends

Writing and Publishing program add a sparkle to her writing and she loves to vary the fonts and rotate the pictures to enhance her stories.

Kristen began on an Apple IIGS. She now uses a Macintosh LC II and is excited about the added flexibility and independence it offers. The programs are installed on the hard drive so she can move from program to program by herself.

She is taking advantage of the built-in Macintosh Easy Access curb cuts, Sticky Keys and Mouse Keys. Sticky Keys allow her to enter keys in sequence instead of simultaneously. This has solved the problem of

having to reach across her body to set and reset the caps-lock key for just one capital letter, which was a major challenge due to her limited range of motion. Mouse Keys allow full access to mouse operations using the number key pad on the right side of the keyboard.

Kristen's class is practicing handwriting, so Kristen is using a script font on the computer to help her learn the letter formations and how to read them.

Co:Writer is a word prediction program for the Macintosh that helps Kristen achieve the speed she was lacking with one-finger typing. The program attempts to predict the next word based on grammar rules and frequency of use. She can choose one of the selected words or continue to type her own choice, which can then be added to the dictionary.

A recent note to her dad about a date at the local Ben and Jerry's Ice Cream Parlor took considerably less time once the name was entered into the prediction section. Seventeen keystrokes were accomplished in just three. As a result of using the word prediction program, Kristen is writing more now that it takes less time to input each word.

Kristen, a talented girl with a supportive family and school system, has a bright future thanks to the use of adaptive computer technology.

Magic Spells and *Children's Writing and Publishing* are available from the Learning Company, (800) 852-2255. *Co:Writer* is available from Don Johnston Developmental Equipment, P.O. Box 639, 1000 N. Rand Rd., Bldg. 115, Wauconda, Ill. 60084, (800) 999-4660.

The Alliance for Technology Access (ATA) is a network of community-based technology resource centers dedicated to providing access to the assistive technologies and related services that enable people with disabilities to achieve productivity, independence and success according to their individual needs and interests. ATA centers serve people of all ages with disabilities of all kinds and have comprehensive, multifaceted programs that reflect their specific community needs, as well as local talents and resources.

For more information about the ATA and the center nearest you, call (800) 992-8111 or (510) 528-0747.

ADVOCACY

- A Victory for Mainstreaming*, Sept. p. 18.
 Accessibility, Dr. Marilyn Phillips and Gregory Solas, Mar. p. M12.
 Advocating for Assistive Technology, Pat Cashdollar, Hall of Fame, Jul/Aug. p. 20; Jackie Brand, Oct. p. 20.
Appearances Count, Helen Reisner, Networking, Sept. p. 64.
Becoming Your Child's Best Advocate, Connie Hawkins, Networking, Sept. p. 63.
Children and the ADA, Stephen Chaikind, Mar. p. M8-M10.
Independent Living Philosophy, Suzanne B. Bacall, Nov/Dec. p. 24.
 Parent Advocates, Fred R. Patterson, Hall of Fame, Jan/Feb. p. 19; Betty Pendler, April/May, p. 16-17; James Autry, April/May, p. 18; Martha Ziegler, Jun. p. 20; Patricia McGill Smith, Sept. p. 28, 30; Gov. Barbara Roberts, Nov/Dec. p. 22, 25.
 Personal Advocacy, Lisa Blumberg, Hall of Fame, Jan/Feb. p. 16-17.
 Wheelchair Access in National Parks, Joel R. Burcat, Apr/May, p. 24-25; July/Aug. p. 42.

BOOK EXCERPTS

- The Americans With Disabilities Act: From Policy to Practice*, Jane West, Mar. p. M58.
How It Feels to Live With a Physical Disability, Jill Krementz, Jun. p. 48-50.
I Will Sing Life: Voices From the Hole in the Wall Gang Camp, Larry Berger, Dahlia Lithwick and seven campers, Oct. p. 50-52.
I Wish... Dreams and Realities of Parenting a Special Needs Child, Kate Divine McAnaney, Sept. p. 86-88.
The Individual Education Planning Committee: A Step in the History of Special Education, William M. Cruickshank, Ph.D., William C. Morse, Ph.D. and James O. Grant, Ph.D., Apr/May, p. 38.
Infancy and Early Childhood: The Practice of Clinical Assessment and Intervention with Emotional and Developmental Changes, Dr. Stanley I. Greenspan, Jul/Aug. p. 50-52.
When Your Child Goes to School After an Injury, Marilyn Lash, Oct. p. 32; Nov/Dec. p. 48.

COMMUNICATION

- Creating Opportunities for Communication*, Patricia L. Mervine, Jun. p. 43-45.
 Facilitated Communication, Bonnie Shoultz, Networking, June, p. 32.
"Mini" Communication Boards, Patricia L. Mervine, Jul/Aug. p. 22-25.

COPING

- 12 Commandments for Parents, Virginia Richardson, Networking, Sept. p. 66.
A Flag-Flying 4th, Gail Williamson, Jul/Aug. p. 32.
 Acceptance, Marianne M. Jennings, Jul/Aug. p. 16; Betsy Rosso-McCurdy, Nov/Dec. p. 16-17.
An Open Letter to Parents of Younger Children, Nancy Fratini, Jan/Feb. p. 32-34.
 Children with Disabilities in the Entertainment Field, Gail Williamson, Jun. p. 22-24.

Electric Wheelchairs: Is It Giving Up or Giving?, Linda Kratz, Oct. p. 26.

Fathers of Children with Disabilities, James May, Apr/May, p. 40-43; Jun. p. 38-41.

Letting Go of Your Young Adult, Carol Tingey, Hall of Fame, Jan/Feb. p. 18, 27.

She Ain't Broke! (so quit trying to fix her!), Nancy Holroyd, Sept. p. 70-74.

Shopping With David, Daniel Lee Mickinac, Mar. p. M48-M49.

Single Parenting, Valerie Bateman, Mar. p. M44-M46.

Social Acceptance, Daniel Lee Mickinac, Jan/Feb. p. 23; Veronica Andrews, Oct. p. 22-24.

Test Child/Real Child, Elizabeth Moon, Jun. p. 16-18.

EDITORIALS

The Americans with Disabilities Act: Dreams for the Future, Mar. p. 12.



Changing Attitudes, Nov/Dec. p. 14.

Changing Practices, Jun. p. 15.

The Family Hall of Fame, Jan/Feb. p. 14.

Good News for Parents and Children: The IDEA Act Thrives!, Sept. p. 12.

Laws and Disability: You Can Make a Difference, Apr/May, p. 14.

Our Children's Future: Preparing Them for Adult Lives, Jul/Aug. p. 14.

Private Programs: An Important Choice, Jan/Feb. p. 55, 62.

You Can Make A Difference: Parents and Politics, Oct. p. 14.

EDUCATION

- 1991 Summer Program Award Winners*, Jan/Feb. p. 20-22.
A Victory for Mainstreaming, Sept. p. 18.
America 2000, Robert R. Davila, Networking, Mar. p. M51-52; Larry Searcy, Mar. p. M54.
An Open Letter to Parents of Younger Children, Nancy Fratini, Jan/Feb. p. 32-34.
Assistive Technology: A Student's Right, Nov/Dec. p. 30-32.
Good News for Parents and Children: The IDEA Act Thrives!, Sept. p. 12.
 Private Programs, Jan/Feb. p. 55, 62.
School Mainstreaming Contest Winners, 1992, Sept. p. 20-23; Oct. p. 30-31.

She Ain't Broke! (so quit trying to fix her!), Nancy Holroyd, Sept. p. 70-74.

Special Education, Sandra Fleishman, Hall of Fame, Mar. p. 14, M50.

Test Child/Real Child, Elizabeth Moon, Jun. p. 16-18.

Unsung Heroes: Special Ed. Bus Drivers, Mary C. Barbera, Sept. p. 24-26.

Visions of the Future, Doreen Pam Stenberg, Networking, Nov/Dec. p. 43.

EQUIPMENT

- Electric Wheelchairs: Is It Giving Up or Giving?*, Linda Kratz, Oct. p. 26.
How Technology Assists My Daughter, Carol Lode, Nov/Dec. p. 34, 41.
Maintaining Your Wheelchair, Mar. p. M14-M16.
Making Your Own Switches, R.J. Cooper, Jan/Feb. p. 46-47.
"Mini" Communication Boards, Patricia L. Mervine, Jul/Aug. p. 22-25.
 Standing Aids, Jul/Aug. p. 28-30.
Van Lifts: A Practical Guide, Marian Hall, Mar. p. M20-M22.

FAMILY RELATIONS

- Financial Stress & the Family, Oct. p. 40-42.
 Problems in Remarriage, Jan/Feb. p. 38-40.
 Problems of Moving the Family, Mar. p. 82-84.
 When Parents Are Children, Jul/Aug. p. 38-40.

F.Y.I.

- CT Scan, *Preparing Your Child for Neurological Testing — Part Two*, Jun. p. 8.
 The EEG, *Preparing Your Child for Neurological Testing — Part One*, Apr/May, p. 8.
 Fragile X Syndrome, *An Overview of Fragile X Syndrome*, Nov/Dec. p. 10.
 MRI Scan, *Preparing Your Child for Neurological Testing — Part Three*, Jul/Aug. p. 8.
 PET Scan, *Preparing Your Child for Neurological Testing — Part Four*, Sept. p. 8.
 Tourette Syndrome, *An Overview of Tourette Syndrome*, Oct. p. 8.

HALL OF FAME

- Advocating for Assistive Technology, Pat Cashdollar, Hall of Fame, Jul/Aug. p. 20; Jackie Brand, Oct. p. 20.
 Parent Advocates, Fred R. Patterson, Hall of Fame, Jan/Feb. p. 19; Betty Pendler, April/May, p. 16-17; James Autry, April/May, p. 18; Martha Ziegler, Jun. p. 20; Patricia McGill Smith, Sept. p. 28, 30; Gov. Barbara Roberts, Nov/Dec. p. 22, 25.
 Personal Advocacy, Lisa Blumberg, Hall of Fame, Jan/Feb. p. 16-17.
 Special Olympics, Eunice Kennedy Shriver, Hall of Fame, Mar. p. 13.
The Family Hall of Fame, Jan/Feb. p. 14.

INDEX — 1991

EP, Jan/Feb. p. 42-43.

MISCELLANEOUS

- Annual Income Tax Guide, Jan/Feb. p. 35-37.
 Incontinence, Jul/Aug. p. 26.
SSA Is Becoming User-Friendly, Jan/Feb. p. 24-26.

1992 EXCEPTIONAL PARENT INDEX

MOBILITY/TRANSPORTATION

Electric Wheelchairs: Is It Giving Up or Giving? Linda Kratz, Oct. p. 26.

Maintaining Your Wheelchair, Mar. p. M14-M16.

Unsung Heroes: Special Ed. Bus Drivers, Mary C. Barbera, Sept. p. 24-26.

Van Lifts: A Practical Guide, Marian Hall, Mar. p. M20-M22.

Your Pet as a Service Dog, Charlene Fickau, Mar. p. M42-M43.

PARENTS SEARCH TOPICS

4p+ chromosome, 49XXXXY syndrome, Aicardi syndrome, Down syndrome with severe delays, eating problems, Friedrich ataxia, incomplete myelination, Marden-Walker syndrome, mystery syndrome - diagnosed spina bifida, looking for Voyager modules, proposed hotel for people with disabilities, ring 22 chromosome, undiagnosed, Oct. p. 8-9, 10, 28, 56.

Abnormal neuronal migration, chromosome 9p disorder, dysgenetic brain/infantile spasms, hemangiomas, hypoxic ischemic encephalopathy — hypothermia and obesity, Lennex-Gestaut & Coffin-Lowry syndromes, Melnick-Needles syndrome, microcephaly, middle of chromosome 5 missing, mysomy 21, Noonan syndrome, pyruvate dismetabolism/Hallervorden-Spatz disease, recreational activities for teens with CP, tetrasomy 15p and partial tetrasomy 15q, VP shunt infections, Apr/May, p. 7-11.

ACTH & increased ventricular fluid, ataxic cerebral palsy, glycogen storage disease, infantile neuroaxonal dystrophy, juvenile myoclonic epilepsy, learning disabilities and gifted, Mobius syndrome, multiple congenital anomalies, spina bifida and hydrocephalus, Sturge-Weber syndrome, undiagnosed, Jul/Aug. p. 8, 10-11, 19.

Achondroplasia and narrowing of the spine, Dandy-Walker syndrome, deletion of long arm of chromosome 4, epidermal nevus syndrome, hypomyelination, pervasive developmental disorders, residential options, surgery for drooling and tongue thrust, walking vs. power wheelchairs, Mar. p. 8, 10, 81.

Agenesis of the corpus callosum, dressing difficulties with back braces, Leber's congenital amaurosis, Miller Dieker syndrome/lissencephaly, one Down syndrome twin, Riley-Smith syndrome, stepparents, spoiled, teeth grinding, trisomy X (47XXX), Tyrosinemia Type III, Jan/Feb. p. 7-8, 10-11.

CP - deaf in one ear, extra narrow shoes, feeding difficulties, friendship for children with ADHD, house accessibility \$\$\$, infantile spasms, intracranial hemorrhage, lupus anticoagulant factor, nonketotic hyperglycemia, recess activities, spina bifida and self-catheterization, swallowing problems, Sept. p. 8, 10-11, 68, 76.

Congenital hypotonia, cytomegalovirus, Down syndrome - walking delays, microcephaly, microcephaly & lissencephaly, prenatal exposure psychiatric drugs, single parent - autism, speech problems caused by stroke, Jun. 8-9, 10-11, 26.

Omphalocele/VATER association and

feeding problems, Opitz-Frias syndrome, parents who have made a placement decision, ring 18 syndrome, static encephaloid and crying episodes, undiagnosed, Nov/Dec. p. 10-11, 26, 23, 51.

POLITICS AND LEGAL ISSUES

America 2000, Robert R. Davila, Networking, Mar. p. M51-52; Larry Searcy, Mar. p. M54.

The Americans with Disabilities Act: Dreams for the Future, Mar. p. 12.

Children and the ADA, Stephen Chaikind, Mar. p. M8-M10.

Estate Planning, Lisa J. Wood, Nov/Dec. p. 18-20.

Laws and Disability: You Can Make a Difference, Apr/May, p. 14.

Parent Advocacy, Hall of Fame, Gov. Barbara Roberts, Nov/Dec. p. 22, 25.

The Presidential Candidates Speak Out, Oct. p. 16-18.

Rehab Reauthorized, Larry Searcy, Networking, Nov/Dec. p. 44.

SSA Becoming User-Friendly, Jan/Feb. p. 24-26.

A Victory for Mainstreaming, Sept. p. 18.

You Can Make a Difference: Parents and Politics, Oct. p. 14.

RECREATION

1991 Summer Program Award Winners, Jan/Feb. p. 20-22.

Accessible Theme Parks, Apr/May, p. 32.

Challenger Little League, Victoria Leclerc Therrien, Apr/May, p. 20-22.

Easter Seal's Camps, Apr/May, p. 34.

EP's Guide to Summer Fun, Apr/May, p. 28.

Special Olympics, Eunice Kennedy Shriver, Hall of Fame, Mar. p. 13.

Toy Resources, Oct. p. 36-38.

Wheelchair Accessible National Parks, Apr/May, p. 36.

RESOURCE GUIDES

Mobility

Accessible Summer Camps, Apr/May, p. 34.

Accessible Theme Parks, Apr/May, p. 32.

EP's Guide to Summer Fun, Apr/May, p. 28.

State-by-State Directory of Accessibility Offices, Mar. p. M18-M19.

Wheelchair Accessible National Parks, Apr/May, p. 36.

Technology

Assistive Technology Centers, Nov/Dec. p. 36-40.

Augmentative/Alternative Comm. Directory, Jan/Feb. p. 28-31; Jul/Aug. p. 34-36.

RESNA Technical Assistance Project, Jun. p. 34-36.

Toys

Toy Resources, Oct. p. 36-38.

TECHNOLOGY BULLETIN BOARD

A Boy and His Computer, Veronica Andrews, Apr/May, p. 45-46.

Creating Opportunities for Communication, Patricia L. Mervine, Jun. p. 43-45.

Increase Your Child's Participation, Patricia L. Mervine, Sept. p. 79-82; Oct. p. 44-46.

Making Your Own Switches, R.J. Cooper, Jan/Feb. p. 46-47.

Unicorn Winner of Johns Hopkins National Search, Jul/Aug. p. 47.

What Health Care Insurers Should Know About Assistive Technology, Gordon Richmond, Mar. p. 79-80.

TIPS FOR PARENTS

Adapting utensils; greeting cards; protecting shoe toes; swimming for very thin children, Apr/May, p. 26.

Adapting wind-up toys; coats for kids in wheelchairs; keeping your child in a wheelchair dry in the rain; G-tube feeding an active child; helping a child with poor motor skills read a book, Jun. p. 56.

Keeping your child's plate in place; bibs; preventing finger-chewing, Mar. p. 90.

Preventing G-tube bacterial growth; handling the G-tube during feeding; using videos to show your child's potential; wheelchair exercise; helping your child sleep away from home; blowing bubbles, Nov/Dec. p. 56.

Transporting medical equipment; coat zippers; getting support & comfort from family; amusing a child during G-tube feedings; G-tube feeding restraint, Jan/Feb. p. 66.

TOY ADAPTATIONS (by Alice Wersching)

ColorBlaster™ by Kenner, Jun. p. 58.

Frog Feast™ by Tyco, Oct. p. 58.

Grabbing Grasshoppers™ by Tyco, Apr/May, p. 59.

Hide and Seek™ by Ravensburger, Mar. p. 91.

Learning Machine™ by Tyco, Jan/Feb. p. 67.

Lil' Yard Blower™ by Nasta, Jul/Aug. p. 58.

Tabletop Arcade Basketball™, Nov/Dec. p. 58.

The Little Mermaid Game™ by Milton Bradley and Disney, Sept. p. 90.

WHAT'S HAPPENING

Disability Rag telethon; guide to federal help for individuals with disabilities; *Physician's Guide to Rare Diseases*, NICHV info. for parents, Sept. p. 84.

L.A. Law episode sparks response: Give Kids the World, Jan/Feb. p. 44.

New picture McMenus; Olympics captioned: ADA recorded for the blind; free flights for cancer patients, Apr/May, p. 48.

Post office honors people with disabilities; Tay-Sachs conference; training service dogs; NCF distributes free tech. equip., Mar. p. M56.

TV spot features sibling with Down syndrome; romance for Corky on *Life Goes On*; pilots donate free medical flights, Oct. p. 48.

University-sponsored speech conference; captioned mainstreaming video; Down syndrome conference planned, Nov/Dec. p. 47.

Very special arts: SSA seeks families for Zebbley Benefits; Down syndrome guide in Spanish, Jun. p. 46-47.

Veterans' kids with disabilities; air travel; free copies of *Seriously Injured* child booklet; Jul/Aug. p. 48-49.

"We continued the school people's fight at home."

Family Problems When Professionals Disagree

"Last week we went to a school meeting about our six-year-old son, John, who has cerebral palsy." Andrea Ackerman, a tall, slender woman in her late 20s, spoke quickly.

"The school people disagree about what kind of program would be best for John. John is in first grade. Mrs. Green, his regular teacher, is always praising John's work. She feels that he has made good progress since September, both academically and socially. He is making friends and his work is average for first grade. But, she was concerned that his work with his three therapists was disruptive both to John and her classroom. Mrs. Green argued that the most important thing for John was to be comfortable and stay focused on his class work.

"Mrs. Green said that the physical, occupational and speech therapists each saw John twice a week. They would often take him out of class in the middle of a lesson or when he was starting a new subject. When he returns to the class, he sometimes has difficulty finding his place and seems disorganized for the rest of the day.

"The therapists disagreed with her. Mrs. Smith, the speech therapist, felt that John has been doing well. His speech is clearer and easier to understand, helping him make friends in the classroom. She felt there would be a relapse or a lack of progress if speech therapy did not continue. Miss Lemon, the physical therapist, and Miss Scully, the occupational therapist, both made the same argument for John from their vantage point. The principal, who sat in on the meeting, seemed unable to referee what was going on. So, at the end of the meeting there was no decision about what to do. They all turned to us and asked us what we thought.

"When we got home, we found

ourselves continuing the argument. Paul and I don't always see eye-to-eye on what's best for John. We had asked the school people if they could find a way to make the visits less disruptive. But they told us that because they see so many other kids, there was no other plan available to them in order to fit his therapy into the school schedule. We asked John what he thought. He said he likes everybody but he looked so upset we did not pursue it with him.

"The question that Paul and I discussed was whether we should do some of the therapy after school and pay for it ourselves. Paul feels that we pay taxes and that these are the services we deserve. The school personnel should solve their own problems. It's up to the team to work these things out.

"This became the center of our disagreements. I think the three of us — Paul, John and I — are working as hard as we can. Sometimes I think less might be better than more. Therapists have always said that John has been a good patient and a good student — he seems to profit from whatever help he gets.

"The school people have been happy with the progress



Illustrations by Robin Courchesne

John has made. It's been more than they expected. He's probably done better than even Paul and I expected. His speech has improved. His ability to move and do things continues to improve. When he comes home at the end of the day, he is exhausted. So, by the time my husband comes home, John is often watching television. Paul gets very annoyed at me for not having more constructive activities planned for John. Paul is reluctant to not take advantage of every opportunity available for John both at the school and in the community on John's behalf. I'm the one who has to do a lot of the running around. I work part time because we really need the money. But I do take John to a lot of the community activities and programs at the library.

"John could take the bus to school but we were concerned about teasing on the bus. We decided we should take him to and from school every day. So, Paul drives John in the morning and I pick him up in the afternoon. Like most kids, he can be very slow in the morning and sometimes Paul just leaves for work and then I have to take John in the morning, too. There are some other activities in the community for kids with disabilities — there's a computer group and a swimming program. But everything requires us to get him there. Right now he's doing well enough in school. Maybe Mrs. Green is right. My feeling is that John's classroom teacher is the key. If she's upset she could take it out on John. Paul thinks it's easy for them to make changes but I'm not so sure it's worth the effort.

"What bothers me is that we have so much to do. Every extra thing, including an extra meeting, feels like too much. Paul and I then waste time arguing about how much we need to do for John. I think we have to begin taking care of ourselves."

"The problem we came to discuss is the disagreement between John's

classroom teacher and the three therapists." Mr. Ackerman, a stocky, dark-haired man in his early 30s, spoke with annoyance in his voice. "It's true that we don't always see eye-to-eye with all that we have to do for John.

"Andrea came home very bothered by the disagreements in the school. When there are disagreements, she tends to back off. She's siding with the classroom teacher to avoid making waves. I, on the other hand, am accustomed to disagreements. My family was one that



"Paul and I don't always see eye-to-eye on what's best for John."

always argued. We just didn't feel that agreeing about everything was necessarily the best place to start. But, disagreement bothers Andrea a great deal. She comes from a family that kept all their disagreements to themselves.

So, we go to a school and people disagree. It doesn't mean that they're not interested in John or won't work for him. It seems like a simple scheduling conflict that they should be able to work out. I expected them to settle their disagreements before talking with us. The bottom line is we have to do what's best for John.

"I think that the more active John is and the more involved he is, the more progress he will make.

People don't do things for people who don't try to do for themselves. Even though John has disabilities, it's a lesson he has to learn. When he was first born, neither one of us had any sense of whether he had a future at all. Now, his future far exceeds what either one of us had dreamed. He's a lot brighter than anybody thought he would be. He is almost at his grade level and I think that if he gets more of the special services he's being given, he'll do even better.

"The other thing that comes up whenever we meet with the various specialists is how much time we devote to John's care and how tired we feel. We both want to do all we can for John. Andrea feels we also have to take care of ourselves. We used to have a good time with our friends and family. The experts never consider us when they make suggestions for John and they probably shouldn't. Pretty soon John will be grown up and we'll have plenty of time for ourselves.

"We're both tired. We don't talk about that, but I'm just as tired as Andrea is. It comes from doing so much. But I just don't know what other choices we have. Either we want to do something for John and make a full commitment or we don't."

Summary and Conclusions

The Ackermans came to discuss the disagreement between school personnel about their six-year-old son John's educational program, which includes physical, occupational and speech therapy. Mrs. Green, John's first-grade teacher, complained that taking him out of class was disruptive to his participation in the classroom and interfered with his school work. The therapists said Mrs. Green's complaint about their work communicated to John that their work was not important.

The school personnel had also placed John in a difficult spot. When the adults in a child's life disagree, they make the child uncertain about who to turn to. Children often don't

continued on page 50

continued from page 49

know which adult to turn to because they're afraid they'll disappoint the others. In this situation, John found himself in the spot of being afraid that while he was with one therapist, he was displeasing the others.

The Ackermans liked each of the people who worked with John. However, Mr. and Mrs. Ackerman had different views about whether the physical, occupational and speech therapy were essential. Mrs. Ackerman felt that cutting back some of this separate work during the school day could be considered. Mr. Ackerman felt that the more extensive the program was, the better off John was. He believed that the problem was between the professionals, and that the principal should make them settle their disagreements.

All parents must decide which activities are essential for their child, and then try to choose among a variety of other activities. Like all parents, the Ackermans had to select which activities were the most worthwhile at any given point in John's life. While some parents may believe that a full range of programs is critical to their child's optimum development, many parents of a child with a disability wonder how much remedial activity is necessary for the child to meet the ordinary challenges of growing up.

Parents of a child with a disability may struggle with defining an adequate program from the day the child is born. They are often presented a range of possible therapeutic programs with the belief that the child will have little chance if he doesn't participate in all of them. However, no professional can guarantee that if a child is engaged in all activities, he or she will profit from each one. This places parents in the difficult position of having to either try programs for their child that may be beyond their own energy or feel guilty not having done enough.

Mr. and Mrs. Ackerman had made a serious commitment to providing the optimum educational and

social environment for their son. They were actively involved in all aspects of his life and programs. They were concerned about how much they could continue to do as well as how little time, energy and money they had to do the things that once gave them pleasure and enjoyment. Professionals tend to focus on the needs of a child when they plan programs while trying to consider the needs of parents. Although they appreciate the additional stresses that a child with a disability can place on



"People don't do things for people who don't try to do for themselves."

a family, they may pay much less attention to the kinds of supports and understanding parents may need. Parents want to be able to participate in their child's program; at the same time, parents have personal needs as adults.

The Ackermans felt vulnerable and uncertain because of the disagreement. These feelings made it difficult to choose among the range of programs that different professionals said were essential.

Parents also have different individual ways of dealing with their own uncertainties and resolving differences. Mr. Ackerman's style was to be very active and involved. He solved problems by doing as much as he could. Mrs. Ackerman was a

more reflective person. She tried to think about what people had told her and tried to get some understanding of what she herself was capable of doing. In general, these different approaches worked well for Mr. and Mrs. Ackerman as they were able to see different sides of a problem.

Mr. and Mrs. Ackerman were reassured about their mutual ability to make decisions. They found it helpful to review the many decisions that had already been made as John progressed. They could understand how uncertainty could make it difficult for anyone to make decisions. They were encouraged to return to the school and share their ideas with John's group of educators and therapists.

Mr. and Mrs. Ackerman understood that when they could agree on a program of action, it was easier for them to work with professionals to make decisions in areas of uncertainty. They went back and told the child's team of workers that they believed they were each doing something important. They wanted them to work out some arrangement that would take into account the concerns of the school teacher, Mrs. Green, as well as John's physical, occupational and speech needs. They were able to make adjustments to everyone's schedule. Some therapy sessions were scheduled after school hours and the Ackermans made changes so they could pick him up later after school.

Over a period of four months, the tensions between the school personnel were reduced by this plan. And John improved in all areas of his program — school, speech and mobility.

— M.J.S. —

This case has been selected from private practice and consultation files. The names and circumstances have been changed to preserve confidentiality.

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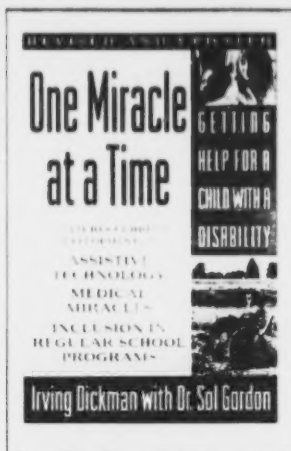
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ONE MIRACLE AT A TIME Getting Help for a Child with a Disability

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The following excerpt from the chapter It's Okay, All the Ways I Feel: The Rights of Parents has been reprinted with permission from the publisher.

You have the right to believe in miracles and to make them happen, just as these other parents do, each in a different way:

- We are just thankful our daughter is with us now. She could have given up at birth, but she's a real fighter, and she's going to try her hardest to fight her disability and be as normal a child as she can possibly be. All I can say to any parent is, please never give up hope for your child.

- We would hope to say "Hang in there" to any parents who are discouraged. A handicap, after all, means only that things will be harder, but not impossible to do. *Never* give up, and *never* allow your child to give up.

- The week of January 15 my five-year-old son Jason said his first complete sentence. It was, "Mama, pretty lights on the wall." I still have some

Christmas lights up in my house; maybe they will be up for a whole year, especially now. Just when you reach the end of your rope, they will do something like this to you.

- I think it is important to take one step at a time ... I would say to take each day as it comes ... Take one day at a time! And when times get real tough, make it through hour by hour! There are plenty of good times to make you forget the bad ... Don't worry about ten or twenty years from now, and what will happen to your child then ... Try to deal with today, and not look too far into the future.

- You'll learn not to take anything for granted. The smallest accomplishments for a normal child can be major steps for yours ... I feel the one thing we have really learned is to appreciate the small things in life that we took for granted with our son: Christina's first step at age two, her first jump at age three years and nine months. There are many many more.

- When some doctors are pessimistic and make statements like "Your child will never speak or walk," we ignore them. If you listened to all that negative talk, what would be the use of trying?

We don't live in a dream world or believe Timmy will be "normal" one day, but we have to help him do as much as possible. He wasn't supposed to speak, but he can say "dada," "hi!" and "mama." And therapists have told us he will probably walk some day.

- *Never* let anyone make sweeping predictions about your child's future. He or she may never turn out "normal," but if you're willing to work real hard, *anything* is fixable. Your goal may have to be 100 percent effort for 2 percent progress, but it *will* pay off. Do your homework and then go for it.

- If you believe in your child and help in his or her struggle, you *will* get some kind of reward. Even that might be just three seconds standing alone ... Never believe anyone who says your child will never walk, talk, go to school, and so forth. Don't give

up hope, even though it is sometimes hard, hard, hard ... Tough times never last. Tough people do.

- We were told that our daughter was brain-damaged and were advised not to search for help such as therapy, etc.; that she would only progress on her own. She cried about fifteen hours a day, disrupted our family life for two years — mother in mourning. Institutionalization was suggested at three months and again at eight months. We rejected the idea, because she was our child. Instead we set up an exercise program ourselves and discovered she was very bright and vocal. She is nine now, and in regular classes, with special education services.

What would I tell parents? To arm yourself with information, to live one day at a time, and to believe in miracles.

The one right that distinguishes you, and bonds you to others like you, like all these other parents of children with disabilities, is the right not to give up. The right never to give up: the right to believe in miracles, great and small, and the right to make them happen if you can.

- I do my best to live in the present. The past is gone, and so be it. The biggest problem is that relatives and some others are always expecting a great miracle: that Chris will walk and talk. This drives me up a wall. Chris has so *many* miracles that don't seem to count for them. He is alive, he communicates, he eats and enjoys it, he loves and hugs and kisses, and he laughs and smiles and is happy.

He has so much to give. He has so much love, so much personality. I tune in to him. I listen with my ears, eyes, head, and heart. When he cries, I tune in and am able to understand. He is terrific and I tell him so. That's what life is about: coping and making the best out of the life we have. My son is doing that.

I don't need him to walk and talk, but I absolutely have to have him smile and give me a kiss. He does! We have had a *different* kind of miracle.

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▼ **"Comforting Your Seriously or Chronically Ill Child"**, Dr. Barbara Morgan & Nancy Gambino. Demonstrates relaxation techniques for children and parents. **\$39.95** (\$5 s&h). NY res. add 8.5% tax. **Better Living Resources**, Box 819, Yaphank, NY 11980, (800) 241-9236 MC/VISA.

▼ **Interax Video Sign Language Course.** Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. **Free brochure.** **\$199** (+ \$4.50 s&h.) **Interax Training, Inc.**, P.O. Box 473106, Garland, TX 75047-3106, (800) 242-5583.

FAMILY SUPPORT

continued from page 12

We have been doing all these things almost daily for two years now.

J.M.R.
 Pennsylvania

Feeding Problems

Response to C.B.'s Parents Search, September 1992.

My daughter was finally diagnosed as being autistic when she was five years old. She was exclusively breast-fed until she was over a year old. She could not eat solid food until then. She also would not drink anything else until she was 18 months old and then only water until she was five. She continued to nurse until that time.

Autistic children tend to be very sensitive to different sensations. A bottle nipple may be painful to his mouth. Have you tried different nipples or perhaps a cup? A feeding syringe may also be a possibility.

Autism is a tricky diagnosis to make, especially in a child so young. Most doctors are unable to recognize it unless the symptoms are obvious. Try to find a doctor or clinic that specializes in autism.

The Autism Society of America (8601 Georgia Ave., Suite 503, Silver Spring, Md. 20910, (301) 565-0433) or the Autism Research Institute (4182 Adams Ave., San Diego, Calif. 92116) should be able to direct you to someone in your area.

An excellent book for information is *Children with Autism — A Parent's Guide*, edited by Dr. Michael Powers. It should give you an idea about whether or not your son is autistic.

At the very least, your son needs early intervention services. Contact Child Find, a free, federally mandated program to educate children with disabilities, in your area and get him into a program. Children with social problems do much better when support services are started early.

K.B.R.
 Maryland

RTS

Rubinstein-Taybi Syndrome Forum Scheduled for July

The First International Family Conference on Rubinstein-Taybi syndrome (RTS) will be held July 16-18, 1993, in the Cincinnati, Ohio area.

The July 1993 conference will be the first time that families of people with RTS will have a national forum for exchanging information and support.

For more information, contact Susanne Bookser, CCDD, Pavilion Building, 3300 Elland Ave., Cincinnati, Ohio 45229, (513) 559-4639.

Retreat to Address Spinal Injury Issues

The third annual Spinal Cord Injury Retreat, sponsored by the Northern New Jersey Spinal Cord Injury System (NNJSCIS), is scheduled for June 1993 at the Kessler Institute for Rehabilitation in West Orange, N.J.

The purpose of the retreat is to provide a forum for the rehabilitation community to discuss current spinal cord injury issues.

For more information about the retreat or to contribute ideas for topics, issues or themes to be addressed, call Diane Gusack, MSW, at (201) 731-3900, ext. 365.

Digest Published about Youths with Disabilities

The National Information Center for Children and Youths with Disabilities (NICHCY) publishes a digest three times a year dealing with disability issues in children and youth.

Recent subjects include sex education, related

services, education laws and speech, occupational and physical therapy.

The 24-page NICHCY *News Digest* contains information complete with references and resources. Individual subscriptions in the United States are free.

For more information or to receive a NICHCY publications list, contact NICHCY, P.O. Box 1492, Washington, D.C. 20013, (800) 999-5599, (703) 893-6061 (in the D.C. area), (703) 893-8614 (TDD).

RESNA

RESNA Announces Conference Plans

RESNA, an interdisciplinary association for the advancement of rehabilitation and assistive technology, has scheduled its annual conference, RESNA '93, for June 12-17 in Las Vegas, Nev.

RESNA '93 will bring together a large number of rehabilitation professionals, products and services from around the world and offer something for both professionals and consumers.

RESNA '93 will be an opportunity for physicians, engineers, technicians, orthotists, prosthetists, educators, university administrators, vocational rehabilitation professionals, business representatives, consumers and therapists to learn, share and network.

For more information, contact RESNA, 1101 Connecticut Ave., NW, Suite 700, Washington, D.C. 20036, (202) 857-1199.

New Tactile Guide to Washington, D.C.

Washington D.C. visitors with visual impairments can now "see" some of

Washington's famous monuments, including the visual layout of the National Mall and the intricate details of the columns and engravings of the White House.

Washington, Symbol and City, a permanent exhibit at the National Building Museum, tells the story of the building of the capital.

The accessible portions of the exhibit, which feature taped and Brailled captions as well as tactile building models of national landmarks, were developed as part of *Capital Sights Not Always Seen*, sponsored by the American Foundation for the Blind.

The National Building Museum is located at 13th and F Streets NW in Washington, D.C.



Project Offers Info on ADA Compliance

The American Foundation for the Blind (AFB) and the National Center for Law and Deafness (NCLD) at Gallaudet University have established a new information service called the Americans with Disabilities Act Communications Accommodations Project.

This project will provide free legal advice and technical assistance to help businesses comply with the ADA and educate individuals with communication disabilities about their rights.

For more information, contact the AFB, (202) 223-0101 or the NCLD, (202) 651-5343.

International Exchange Program Recruits Delegates

Mobility International USA (MIUSA) is recruiting delegates for two outbound youth exchanges, one to Bulgaria and the other to the republics of the former Soviet Union.

These educational exchanges are scheduled for the summer of 1993. MIUSA is currently seeking persons with and without disabilities between ages 16 and 25. Partial scholarships are available.

For more information, send a letter with name, address and the program of interest to Mobility International USA, P.O. Box 3551, Eugene, Ore. 97403, (503) 343-1284.

European Camping Holidays Available

The Access Foundation has announced its 1993 camping holiday programs in France and England for persons with mobility impairments.

Various destinations and activities are available to wheelchair users between ages 12 and 25. Family members and friends may accompany them.

Programs include sailing, nature outings, sightseeing, sports, recreation and swimming.

Access is a nonprofit organization which offers travel services and programs at reduced prices.

For more information, contact Access: Camping, P.O. Box 356, Malverne, NY 11565-0356, (516) 887-5798 (voice/fax).

ORGANIZATION NEWS

Moved

• National Support Group for Polymyositis/Dermatomyositis, 252 Platt Creek Rd., Hazelwood, NC 28738, (704) 456-8207.

SCHOOLS, CAMPS & RESIDENCES DIRECTORY

Arizona

Devereux Arizona

6436 East Sweetwater Avenue
Scottsdale, AZ 85254
(602) 998-2920

Residential and day programs for children and adolescents with emotional disorders and/or learning disabilities.

Hacienda de los Angeles, Inc.

1402 East Mountain Ave.
Phoenix, AZ 85040
(602) 243-4231

State-of-the-art care for medically fragile children and adults. A federally certified intermediate care facility for MR, advanced medical care consisting of 24-hr. skilled nursing, respiratory care, in-house PT and OT
see ad page 63

California

Devereux Santa Barbara

P.O. Box 1079
Santa Barbara, CA 93102
(805) 968-2525/(800) 359-7979
Res., day, and comm. progs. for children & adults who have a wide range of developmental disorders and/or emotional disorders.

Connecticut

Devereux Glenholme

81 Sabbaday Lane
Washington, CT 06793
(203) 868-7377

Residential treatment ctr. for children and adolescents, 5-15, with emotional disorders, incl. ADD and learning disabilities.

Riverbrook

108 Glen Road
Stockbridge, MA 01230
(413) 298-4926

Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

Delaware

Devereux Wrangle Hill

3560 Wrangle Hill Road
Bear, DE 19701
(302) 834-8416

A res. prog. for children with emotional disorders (placed in care by the Del. Div of Child Mental Health).

District of Columbia

Devereux Children's Center

3050 R Street, NW
Washington, DC 20007
(202) 282-1200

Res. treatment svcs. for children with emotional dis., ages 6-12, who have been referred by the Dept. of Human Svcs., Washington, D.C.
see ad page 67

Florida

Devereux Florida Treatment Network

Hospital, res. community and day prog. for children and adolescents with emotional, conduct and developmental disorders. Special services: therapeutic foster care, outpatient/in-home services. Available

Devereux Hospital and Children's Center

8000 Devereux Drive
Melbourne, FL 32940
(407) 242-9100

Devereux Orlando Center

6131 Christian Way
Orlando, FL 32808
(407) 296-5300

Georgia

Devereux Georgia

1291 Stanley Road, N.W.
Kennesaw, GA 30144
(404) 427-0147/(800) 342-3357
Psychiatric hospital/intensive residential treatment program for adolescents who have emotional, behavioral and/or learning disorders.

Kansas

Institute of Logopedics

2400 Jardine Drive
Wichita, KS 67219
(800) 835-1043

Res. school for children 5-21 with multiple disabilities. Intensive speech, physical, and occupational therapies avail. Evaluation options and treatment planning avail. Emphasis on transition to home environment. Summer and full year.
see ad page 59

Maryland

Devereux Resources for Special Children

9515 Reisterstown Rd.
Owings Mills, MD 21117
(410) 363-3100

Info. and support resource to clients/families - inc. eval./admissions, prog. planning and post-discharge, family counseling, ed. training.

Massachusetts

Berkshire Children's

Community, 249 N. Plain Rd.
Housatonic, MA 01236
(413) 528-2523

For children who are severely retarded, multiply disabled. Private, nonprofit, residential school located in the Berkshires.

Cardinal Cushing School

and Training Center
400 Washington Street
Hanover, MA 02333
(617) 826-5371

Provides academic, res. and vocational prog. for all levels of developmentally delayed students to help them lead fulfilling, productive lives. Prog. incl. Prader-Willi Syndrome and international students. Ages 6-22.
see ad page 61

Crystal Springs School

38 Narrows Rd., Box 372
Assonet, MA 02702
(508) 644-3101, Ext. 328

Established in 1953, Crystal Springs offers licensed homelike residences: an approved private school; full rehab program; and 24-hour licensed nursing coverage designed to meet the needs of medically fragile, multihandicapped children and young adults, birth-22 years.

Devereux Massachusetts

60 Miles Rd., P.O. Box 197
Rutland, MA 01543-0197
(508) 886-4746

A residential program for children, adolescents and young adults who have emotional disorders and developmental and learning disabilities.

League School of Boston, Inc.

225 Nevada St.
Newtonville, MA 02160
(617) 964-3260

Offers 12-month day educational prog. specialized com. residences, early intervention home training, comm.-based supportive employment & vocational training, after-school rec. prog. and friendship farms.
see ad page 61

The New England Center for Autism

33 Turnpike Road
Southboro, MA 01772
(508) 481-1015

Day/residential school for children with develop. disabilities, behavior disorders age 3-22. Integrated preschool, inclusion svcs., staff intensive prog., functional activity based curr., supported employment in modern school and group homes.

New England Villages Inc.

664 EP School Street
Pembroke, MA 02359
(617) 293-5461

Private residential community for adults with developmental disabilities. Vocational, recreational programs.

Riverbrook

108 Ice Glen Road
Stockbridge, MA 01230
(413) 298-4926

Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

Minnesota

Camp Buckskin

3811 W. Broadway
Attn: EPM
Minneapolis, MN 55422

Specializes in children with LD, ADHD or EMH ages 6-18. Program actively seeks to develop self-confidence, improve social skills and enhance self-concept. Individualized attention and encouragement promote success in academics and traditional camp activities!

New Jersey

Devereux Center for Autism

186 Roadstown Rd.
Bridgeton, NJ 08302
(609) 455-7200

A residential program for individuals, 8 to 22, who have mild to severe mental retardation.

Devereux Deerpark

230 Pottersville Rd., P.O. Box 520
Chester, NJ 07930
(908) 879-4166

Residential and day programs for females, 10 to 21, who have emotional and behavioral disorders and learning disabilities.

SCHOOLS, CAMPS & RESIDENCES DIRECTORY

New York

Camp Huntington

56 Bruceville Road
High Falls, NY 12540
(914) 687-7840

A co-ed res. camp for learning disabled, ADD, neurologically impaired and mild-moderate MR located in the Catskill Mts. of NY state.

Devereux New York

Route 9, P.O. Box 40
Red Hook, NY 12571
(914) 758-1899

A residential prog. for individ., 8 - 21, who have develop. disabilities, emotional dis., neurological impairments and/or Prader-Willi syndrome.

Pathfinder Village

Box 32-A
Edmeston, NY 13335
(607) 965-8377

Opportunities abound in this colonial style village that provides quality life experience for children and adults with Down syndrome.

see ad page 64

Riverbrook

108 Ice Glen Road
Stockbridge, MA 01230
(413) 289-4926

Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

North Dakota

Anne Carlsen School

301 Seventh Avenue, NW
Jamestown, ND 58401
(701) 252-3850

Here young people with disabilities can achieve their highest potential. Many programs for intensive evaluation and intervention.

see ad page 65

Pennsylvania

Devereux Brandywine

Devereux Road
Glenmoore, PA 19343
(215) 942-5968

Residential/day prog. for males, 6 to 21, who have emotional ADD and conduct disorders. Special services for hearing impaired.

Devereux Day School

Leopard Road
Berwyn, PA 19312
(215) 296-6843

Day program for children & adolescents who have social and emotional disorders and/or brain injuries.

Devereux French Center

119 Old Lancaster Rd.
Devon, PA 19333
(215) 964-3269

Res. prog. for adolescents and adults with social/emotional dis., neurological impairments, traumatic head injuries and dual diagnoses.

Devereux Health Services/Comm. Prog. Ctr.

600 Boot Rd.
Downingtown, PA 19335
(215) 873-4945

Res. prog. (incl. group homes) for adults with develop. disabilities & dual diagnoses. Special svcs: adult day placement & respite care.

Devereux Kenner Center

390 E. Boot Rd.
West Chester, PA 19350
(215) 431-8174

Residential programs for children, adolescents and young adults who have MR, developmental disabilities and emotional disorders.

Devereux Mapleton Center

655 Sugartown Rd., Box 297
Malvern, PA 19355-0297
(215) 296-6970 / (800) 433-1184

Residential and in-patient prog. for children, adolescents and young adults with emotional disorders, LD and neurological impairments.

Devereux Pocono Center

R D. #1, Box 27A
Newfoundland, PA 18445
(717) 676-3237

Residential and day care programs for adults who have emotional disorders, developmental disabilities and mental retardation.

H.M.S. School for Children with CP

4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566

Residential/day school prog. for children 2-21 who are severely physically disabled by CP. Integrated therapies. Assistive tech.

Martha Lloyd Community Services

190 W. Main Street
Troy, PA 16947-1199
(717) 297-2185

A private residential program for ambulatory mentally retarded women, ages 15 and older. Emphasis on vocational and community life skills training. Homelike community residence in north central Pennsylvania.

Rhode Island

Riverbrook

108 Glen Road
Stockbridge, MA 01230
(413) 298-4926

Res. facility for 22 moderately mentally handicapped women, program emphasizes self care, social, rec. & voc. skills. No upper age limit.

Tennessee

Devereux Genesis Learning Centers

430 B Allied Dr.
Nashville, TN 37211
(615) 832-4222

Day school and treatment prog. for adolescents and young adults who have emotional disorders, mental retardation & learning disabilities.

Texas

Devereux Hospital and Neurobehavioral Institute

1150 Devereux Dr.
League City, TX 77573
(713) 335-1000

Acute care hospital, small living units, school for ind. with severe emotional and/or conduct dis., pervasive dev. dis., brain injuries.

Devereux Psychiatric Residential Treatment Center

120 David Wade Drive
Victoria, TX 77902-2666
(512) 575-8271 / (800) 383-5000

Res. prog. for those with emotional, behavioral dis. Including a specialized psychiatric hospital/intensive residential treatment program.

Wisconsin

Chileda Habilitation Institute

1020 Mississippi St.
LaCrosse, WI 54601
(608) 782-6480

Res. treatment ctr. training & intensive therapy for children w/ severe mental & physical disabilities.

St. Coletta School

W4955 Highway 18
Jefferson, WI 53549
(414) 674-4330

Year-round res. prog. in academic instruction & prevocational training for MR/DD. Adult res. facility w/ work opp. for aging MR/DD.
see ad page 58

To advertise in
Exceptional Parent's
Schools, Camps & Residences
Guide, call Melissa Fowler at
(800) 852-2884

The power to become.



*With a lot of determination
and the help of Easter Seal
quality rehabilitation
programs, millions
of people are
living better lives.*

*Give the power to become.
Support Easter Seals.*





Is Everyone Focusing On The Negative?

It happens all too often to children with special needs.

At Cotting School, we focus on your child. Building the skills he has. Helping him acquire new ones. And nurturing his self-esteem.

We can build opportunities for your child to view himself positively.

Cotting is a private non-profit, Chapter 766 approved co-educational day school offering educational and therapeutic services to meet a wide range of special needs.

Call us at our new campus in Lexington at (617) 862-7323. Please ask for Department A.

Cotting School

We focus on your child.

For boys and girls with learning, physical, communication or medical needs
453 Concord Avenue, Lexington, MA 02173
(617) 862-7323

What readers are saying about *Exceptional Parent*

"*Exceptional Parent* ... is the finest publication of its kind ... must reading for all those with a handicapped child. It could change their lives.

Ann Landers

Reprinted with permission of Ann Landers, Los Angeles Times Syndicate/Creators Syndicate

I highly recommend *Exceptional Parent* magazine to all parents of children with disabilities."

T. Berry Brazelton, M.D.

Clinical Professor of Pediatrics

Harvard Medical School

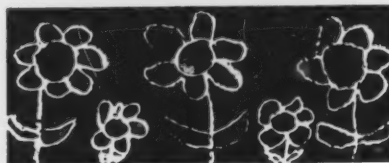
Author of Doctor and Child, On Becoming A Family, What Every Baby Knows, Infants and Mothers, Toddlers and Parents

Each person is a unique individual with God-given potential to live a personally satisfying, productive life. At St. Coletta's, we not only believe this, but we act on our belief. Each of our students and adult residents receives the kind of personal attention they might expect to receive from their own family. Their education, home life, recreation and leisure activities, vocational training and employment are planned to make the most of their individual interests and abilities. We are a caring community where each of us shares a loving concern for one another. In a world where love is sometimes in short supply, we have it in abundance.

St. Coletta School, founded in 1904, offers a year-round academic residential program for children and young adults (ages 6-25) with mental retardation. Special services include personal and vocational counseling, socialization skills,

In A World
Where Love
Is Sometimes In
Short Supply

We Have
It In
Abundance



St. Coletta School

W4955 Highway 18
Jefferson, Wisconsin 53549

personal living skills, transitional home living, speech and language development, music and art, adaptive physical education and swimming, and physical and occupational therapy.

Our Alverno ICF/MR program provides superior quality care for adult residents in a pleasant, attractive setting. Wholesome meals, attentive staff, and stimulating activities are among the things which make Alverno of special interest to families seeking comprehensive care.

Other St. Coletta programs include habilitation/vocational training, employment opportunities for adult workers, and community transitional group homes. For further information, contact the Admissions Office at (414) 674-4330.

FAMILY SUPPORT

continued from page 18

After several EEGs and MRIs, the doctors informed us that Shane's entire brain had been infected with the virus. His prognosis didn't look good. They said Shane would most likely have severe mental retardation and would probably develop contractures.

Shane is starting to show an ability to interact. He smiles and is trying to make some sounds. Every little smile or movement is such a big deal to us.

But Shane is definitely going to have a lot of serious problems. He may never walk or talk or do much of anything. The hardest part for families is waiting and not knowing what the future holds for your child.

I would like to correspond with other parents of a child with herpes encephalitis. It is a rare disease and I have been unsuccessful in locating any support groups or any families who have experienced what our family has.

We do not know how Shane became infected with the virus. Neither my husband nor I have any history of herpes.

L.P.
Ohio

Parents Search is an opportunity for our subscribers to get information from parents about their practical experience in handling the everyday problems of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

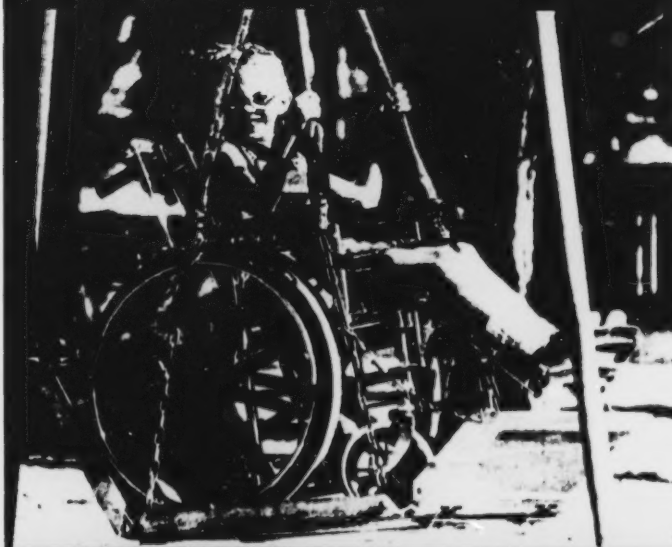
Anyone who wishes to submit or reply to a letter in *Parents Search* or *Respond* should write to:

Exceptional Parent
1170 Commonwealth Ave., 3rd Floor
Boston, Mass. 02134-4646.

Please indicate whether it is a **search** or **response** letter and in which issue the original letter was printed when addressing a reply. All responses will be forwarded and may be published in our *Parents Respond* column.

For technical information about a disability, we encourage you to contact NORD (P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518) or refer to *The Annual Directory of National Organizations, 1992-93*, in the September 1992 issue of *Exceptional Parent* (available from the above address for \$6 including postage and handling).

The Joys Of Summer



...Begin With A Program.

Amanda could hardly contain herself as they set her chair into the wheelchair swing...it seemed like she'd been waiting for this for a hundred years. She gripped the swing tightly between her fingers, took a deep breath and said, "I'm ready!" Then, as they put the swing into motion, her hesitant smile became an ear-to-ear grin. For the very first time in her eight-year-old life, Amanda was swinging.

For Amanda and others like her, our special seven-week summer program is a place where children with multiple disabilities, age 6-22, can discover the joys of achievement.

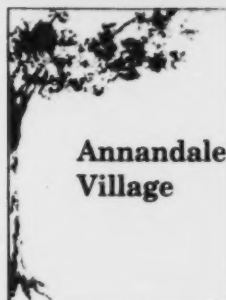
The opportunity to make new friends...learn new skills...and increase independence awaits! We combine functional education, individualized therapies, exciting recreation activities and caring, professional services for a summer full of smiles.

Enroll Now For Summer '93!

Summer Session: June 21-August 6
Application Deadline: April 1, 1993

 **Institute
of Logopedics**

...reaching for potential.
2400 Jardine Drive
Wichita, Kansas 67219
1-800-835-1043



"THEIR COMMUNITY ... WITH OUR HELP" Private, nonprofit community for developmentally disabled adults offering residential/non-residential transitional programs and services.

- Job Training • Arts Activities.
- Therapeutic recreation.
- Case management.
- Founded 1969.
- 125-acre wooded environment.

Contact: **Annandale at Suwanee, Inc.**
3500 Annandale Lane, Box 7
Suwanee, GA 30174
(404) 945-8381

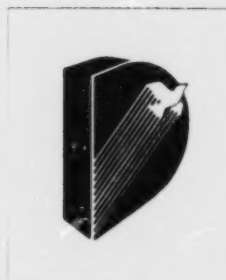


A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPER.
A co-ed residential camp for the:

- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 31st year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
P.O. Box 3789
Poughkeepsie, NY 12603
(914) 687-7840



WORKING TOGETHER FOR A BETTER FUTURE! In residential, day and community-based treatment centers nationwide, Devereux provides comprehensive services to individuals of all ages who have:

- Emotional disturbances.
- Developmental disabilities.
- Mental retardation • Dual diagnosis.
- Autism • Post-head trauma.

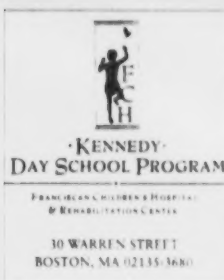
Contact: National Referral Services
The Devereux Foundation
(800) 345-1292, ext. 3045
(215) 964-3045
(215) 971-4600 (FAX)



THE DUVAL HOME, EST. 1945.
A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory mentally handicapped of all ages:

- 24-hour nursing care.
- Lovely 24-acre rural campus.
- Recreational and training activities.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 36
Glenwood, FL 32722
(904) 734-2874



"CARING FOR CHILDREN WITH DISABILITIES: CHALLENGES IN REHABILITATION." Join us at our March 26, 1993 Conference held at the Vista International Hotel in Waltham, MA. Call: (617) 254-3800, Ext. 1510.

- Rehabilitation programs for children and adolescents with disabilities.
- General pediatric care.

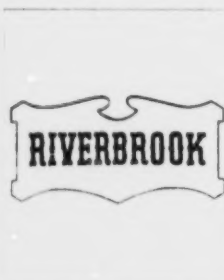
Franciscan Children's Hospital
30 Warren St., Boston, MA 02135-3680
(617) 254-3800/TDD (617) 254-6835
Rehab. Referral (800) 333-4KID



"MAXIMIZING INDIVIDUAL POTENTIAL"

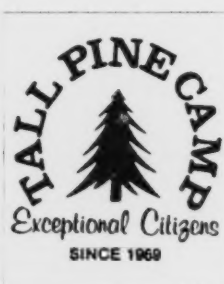
- Community-based, private day/residential treatment.
- Positive behavioral management.
- Ages 8-22, multiply handicapped, mentally retarded, behavior disordered, autistic & hearing impaired.
- 12-month program.
- 10 miles west of Boston.

Contact: Student Services Coordinator
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000



RIVERBROOK
A private residential facility designed to meet the needs of women who are moderately mentally handicapped. The gracious estate houses 21 clients in a warm, family atmosphere.

Contact: Joan Burkhard
Riverbrook
Ice Glen Road
Stockbridge, MA 01262
(413) 298-4926



TALL PINE CAMP. Co-ed mountain camping for children and adults with MR. Programs and activities based on individual abilities. Prof. staff, two full-time nurses. Self-care & social skills emphasized. Academics, incl. computer programming. Many recreational activities avail.: swimming, crafts, boating, equestrian prog., etc. 2, 3, 6 wk. sessions avail. for \$300/wk.

Contact: Ron & Cammie Eydt
Tall Pine Camp, Rt. 2, Box 194-A
Tellico Plains, TN 37385
(615) 261-2324

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Accreditation: Massachusetts Dept. of Education, Office for Children; Dept. of Social Services; Dept. of Mental Retardation; Dept. of Mental Health; NY Dept. of Education

Anyone who has ever visited the Cardinal Cushing School and Training Center and Braintree St. Coletta Day School will no doubt express that the experience was inspirational. The two programs, operated by St. Coletta's of Massachusetts, are reminders that miracles can happen when exceptional children are not treated as mentally disabled.

Established in 1947, St. Coletta's has blossomed into two distinct schools with over 200 staff members. The philosophy of the organization is to provide an environment where developmentally-delayed children can develop their abilities in an atmosphere of confidence and joy. Today, the schools offer what may be the best educational programs available to exceptional children, consistently producing amazing results.

At the Braintree St. Coletta Day School, approximately 70 students ages 5-22, enjoy a staff ratio of 1-3 which enables instructors to provide a high degree of personal interaction. From occupational education and behavioral management - to the development of social and domestic skills - activities enable students to gain the highest possible degree of independence. A residential component is also available.

Exceptional Schools

**Braintree St. Coletta
Day School**

**Cardinal Cushing School
and Training Center**



St. Coletta's
OF MASSACHUSETTS

John W. Shyne, Jr., President
(617) 826-6371
Hanover, MA

Located in Hanover, the Cardinal Cushing School and Training Center provides roughly 160 students with academic, vocational, and residential programs for all levels of developmentally-delayed children and young adults ages 6-22. With residential placement for 130 students - accommodating 30 day attendees - the programs guide students to a chosen career by instilling in them the academic, functional and social skills.

From culinary arts and hotel maintenance, horticulture, maintenance and more, students receive hands-on training. In addition, programs in theater and sporting, as well as the benefits of living alongside peers, further increase social development. After leaving the school, most students are able to find employment. In fact, a notable alumni is Chris Burke, star of the ABC TV series "Life Goes On," introduced to performing arts through the school.

• • Services Include • •

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Vocational Training
Independent Living Training
Adaptive Physical Therapy
Speech Therapy • Counseling
Community Skills • Summer Programs
Bi-Lingual (Spanish) Program

continued from page 40

however, still claim a standard deduction which will depend on his or her income and disability. The deduction allowed is the greater of \$600 or the dependent's earned income. The maximum deductible is \$3,600. If your child has vision impairments, however, he or she is eligible for an additional \$900 deduction.

General Tips on Filing

If you are thinking of not filing your tax return for fear of being unable to pay any taxes owed or have not filed a return in the past, the IRS urges you to file. Individuals and businesses who voluntarily reenter the tax system, or enter for the first time, will find the IRS eager to help them file the necessary tax returns. Although the IRS is not offering an amnesty program, they will work out installment payments and offer compromises to help nonfilers who cannot pay their liability in full. If you do not file a tax return in any given tax year, interest and penalties simply continue to accrue on amounts owed. Nonfilers could also be due refunds which they may lose if not claimed within three years from the time the return was due.

The IRS is prepared to offer assistance to nonfilers. Local IRS offices have copies of prior year federal tax forms and employees have been trained to help taxpayers reconstruct old records, such as income statements, needed to prepare old returns. For additional

information, nonfilers should call (800) 829-1040 or visit their local IRS office.

Tax Planning

By planning ahead, parents can decrease the amount they pay in taxes. For example, some child-care expenses may also qualify as medical care. If child-care expenses exceed the credit limitations of \$2,400 for one child or \$4,800 for two or more children, some of the excess expenses may be considered medical care and therefore be used as a medical deduction. For example, if a family spends a total of \$6,500 to care for their three children, the credit can be applied to only \$4,800. If some of the care can be considered medical care for your child with disabilities, some of the extra \$1,700 can be used as a medical deduction.

C.C. & J.L.R.

To order the following free IRS publications, call (800) TAX-FORM.

- #502: Medical and Dental Expenses
- #503: Child and Dependent Care Expenses
- #596: Earned Income Credit
- #907: Tax Information for Persons with Handicaps & Disabilities.

Special thanks to Arthur J. Sauter and Marti Melicio for their help in preparing this article. Sauter is a CPA at Deloitte & Touche in Minneapolis, Minn., and his article, *Tax Considerations for Parents of Disabled Children*, appeared in the Winter 1992 issue of Meeting Ground, a newsletter published by the Courage Center, 3915 Golden Valley Rd., Golden Valley, Minn. 55422. (612) 588-0811. Melicio is public affairs officer at the IRS Office in Boston, Mass.

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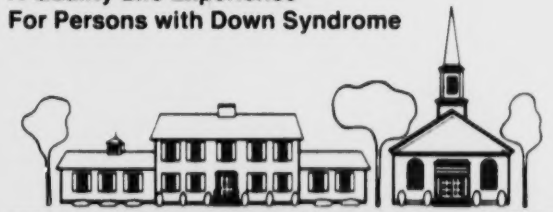
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Persons with disabilities come in all ages.

Because needs are not limited to traditional "school years" Anne Carlsen School serves persons throughout their lives. There are no age barriers.

Once, Anne Carlsen School was one of the few alternatives for young people with disabilities. Parents brought their children, often from great distances, for the education and therapies the school provided.

Many children stayed throughout their school years, growing into young adults who could live independent lives and make contributions to their families and society. They also spent many months of the year away from their families and home communities.

More recently, mainstreaming has brought services to the child. Today's parents, special educators and therapists know the value of a loving family and supportive friends and neighbors to children of all ages and abilities.

Today, Anne Carlsen School serves children for shorter stays. As always, we are committed to providing high quality individualized education and rehabilitation. We offer loving care and support to the students we serve as well as vocational training and assistive technology.

We work in cooperation with our student's local school district. Public schools are aware of their responsibility to serve children with special needs and many do a wonderful job of providing these

services. But sometimes certain services are not available. Whether because of the lack of specialized staff or technology, or because of the cost of the services, the child isn't receiving the type or amount of rehabilitation needed.

Anne Carlsen School augments services provided by the child's home school district. Through extensive diagnostic evaluation and therapy, we determine the child's specific needs and the rehabilitative answers to their challenges. Students no longer spend all their school years here. We diagnose their needs, recommend the therapy program and send them home with the tools needed for success at home and in school.

And, it doesn't stop there. A young child may come here for evaluations to help his parents to prepare for school. The same child, during the school years may outgrow a program, need updated technology, or want to try some different equipment. During and following high school, the young person may come here for help on daily living skills. Later, job training may be the focus of another short stay.

Anne Carlsen School is a resource center for people with disabilities of all ages. We are also a resource for the families of people with special needs. Do you want to know more about your child's needs? Do you want to talk about the impact of your child's disability on your family? Do you want to find parents of other children with special needs? Does your child's teacher have questions about technology?

**Anne Carlsen School can help.
Call toll-free (800) 568-5175**

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**AnneCarlsen
School**

Art in Suspense

by Alice Wershing

In the creative process, we usually start out with an idea of how we want our finished product to look. Imagine creating something without knowing how it will turn out. What would it be like to have colored pens within reach but never touch them during the drawing process? Wouldn't it be fun to have each drawing come out a complete surprise?

Spirograph Suspension Art™ by Kenner does exactly that. A plastic archway suspends a hanging platform below a weighted colored pen. The string that suspends the platform under the arch allows the platform to swing while the pen moves back and forth across a sheet of paper. Depending on how the platform is moved, the drawing pen will perform geometric contortions while creating a work of art.

Suspension Art may not need many modifications for some youngsters. The broad platform offers a wide base for many artists to grab with one or two hands. It also moves easily with just the push of an arm, elbow, wrist or even a nod of the head. However, you may have to figure out how to place the toy in relation to the user.

The following suggestions may provide additional stability:

① Stabilizing the Archway.

Supplies needed: Blocks of wood, clamps or VELCRO™

Mount the archway onto blocks of wood. The blocks can then be clamped to a table edge or fastened with VELCRO™ to a carpet for use at floor level.

② Adding a Handle.

Supplies needed: Strong floral wire, pipe insulation

Adding a sturdy handle may offer stability when pushing the platform. Instead of pushing the platform, some youngsters may find it easier to hold the platform and slowly move it to create their masterpieces.

There are small indentations at each corner of the platform to allow the suspension string to wrap around, holding the platform as it swings. This indentation area is perfect for inserting one end of the floral wire, while bending it around the front of the platform edge. Bending the wire allows it to conform across the edge of the platform until it reaches the other edge. The wire can then be tucked into the slot holding the string. Covering the wire ends with duct tape will ensure safety. Simply bending the wire outward toward the user will provide a handle that can be pulled by some youngsters.

③ Additional Stability.

Supplies needed: Pipe insulation

Pipe insulation may be cut to the appropriate length and split down the middle. The insulation can then be placed over the wire, offering a wider grasping area.

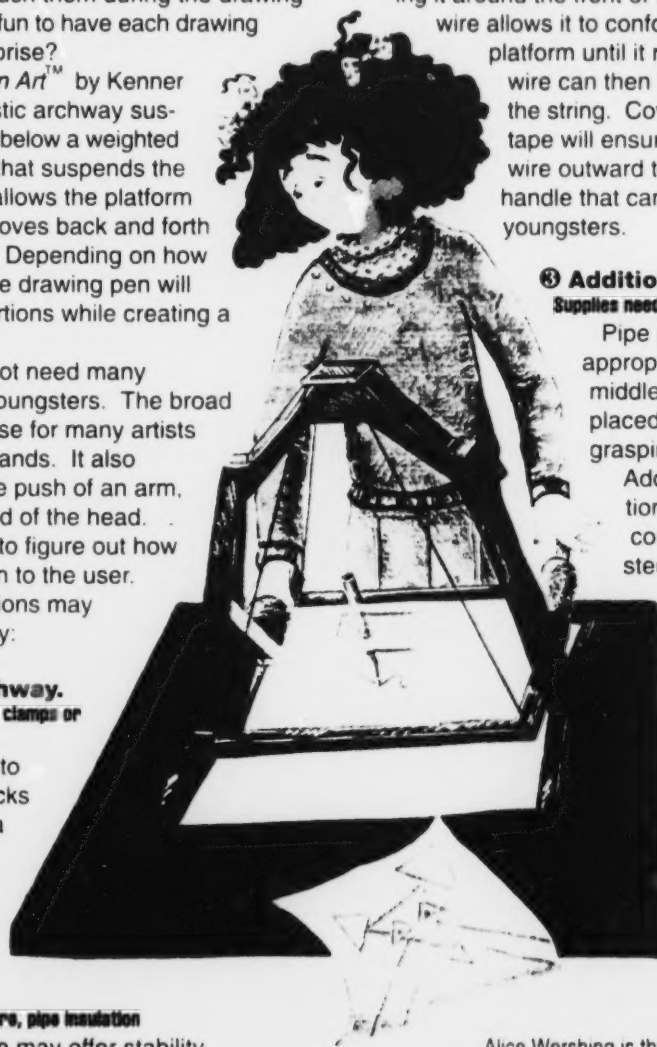
Additional pieces of pipe insulation can be cut and placed at the corners of the platform for youngsters who prefer pushing and pulling the platform rather than letting it swing.

Most youngsters will need some assistance in placing and changing the weight on the pens.

For additional fun and creative drawings, try hanging the platform at varied lengths and see what happens!

Spirograph Suspension Art™ is available at Toys R Us stores.

Alice Wershing is the Computer Resource Specialist and Toy Program Coordinator at the Disabled Children's Computer Group (DCCG): Technology Resources for People with Disabilities, 2547 Eighth Street #12A, Berkeley, Calif. 94710. (510) 841-DCCG.



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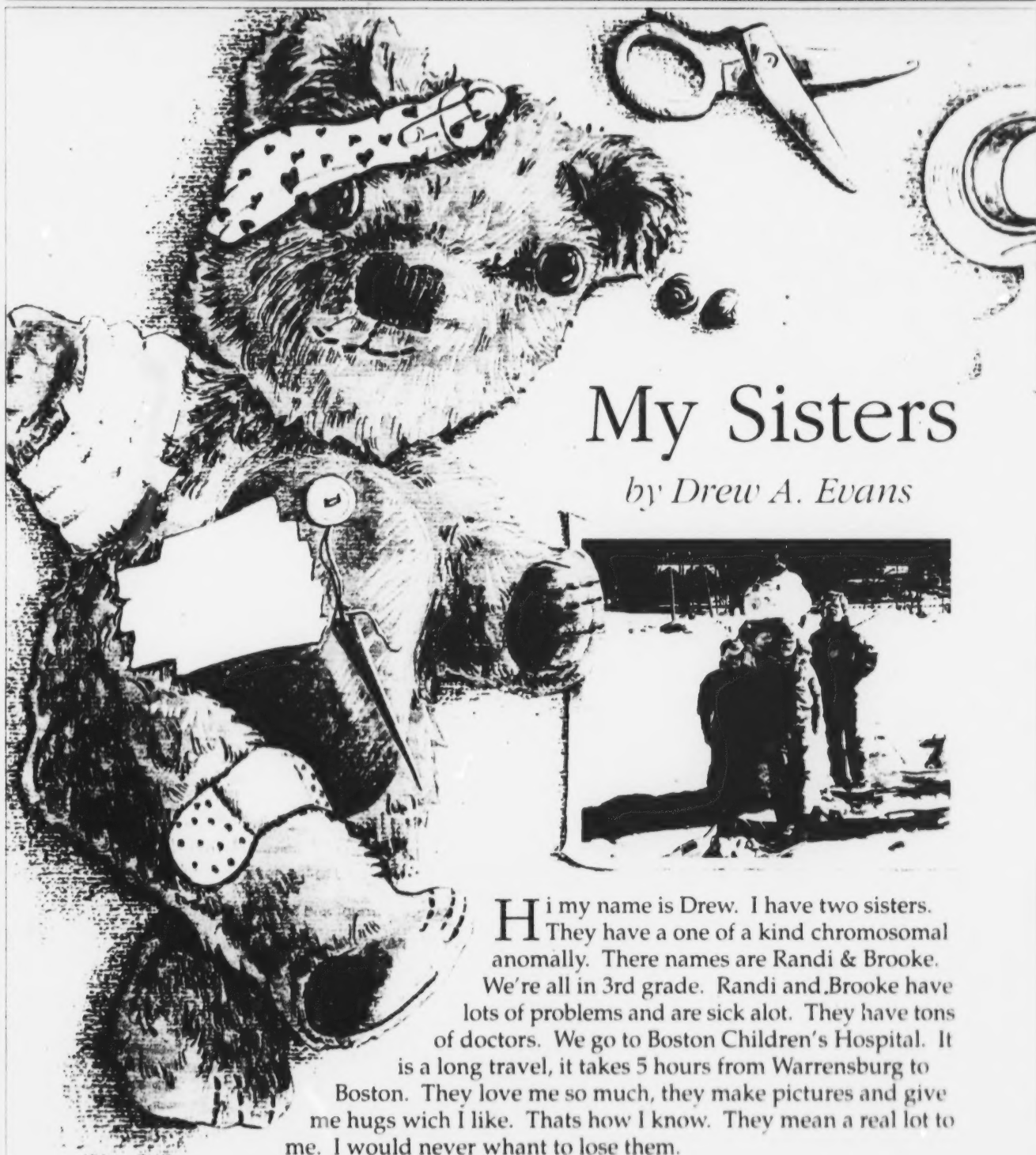
Contact: National Referral Services

1-800-345-1292, X3045 or

215/964-3045

FAX: 215/971-4600





My Sisters

by Drew A. Evans



Hi my name is Drew. I have two sisters. They have a one of a kind chromosomal anomaly. Their names are Randi & Brooke. We're all in 3rd grade. Randi and Brooke have lots of problems and are sick alot. They have tons of doctors. We go to Boston Children's Hospital. It is a long travel, it takes 5 hours from Warrensburg to Boston. They love me so much, they make pictures and give me hugs wich I like. Thats how I know. They mean a real lot to me. I would never want to lose them.

Drew A. Evans, 8, lives in Warrensburg, N.Y. with his parents, Cathy and Charles. His sisters Randi, 10, and Brooke, 9, both have a chromosomal anomaly called 9p+, with a partial deletion on the upper arm of their ninth chromosome. They also have a small amount of extra chromosome attached to the ninth chromosome. The doctors say the two girls are the only known cases in the world. Drew, Randi and Brooke are very close and do practically everything together, their mother reports. They are all very "into the medical terminology which surrounds the girls' problems, treatments, testing, etc." They particularly enjoy playing pretend hospital, using their stuffed animals and real animals. The Evans family has a dog, puppy, cat and three rabbits. Drew, Randi and Brooke appeared on the cover of the November/December 1992 issue of *Exceptional Parent*.

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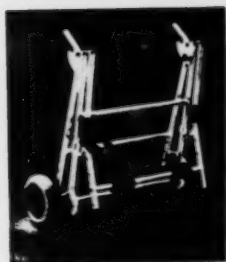
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Cover: Clinton Chat Anastasia Somosa talks to President Clinton on an ABC-TV kids' special. Photo by Steve Fenn

March 1993

Volume 23, Number 3

FEATURES

- 16 Family Hall of Fame** *Exceptional Parent* inducts Jan Little for her work developing and evaluating adaptive equipment over the past 20 years.
- 18 Finding Funding for Assistive Technology**
A guide to helping families find financial resources to buy adaptive equipment.
- 30 Insurance Claim Appeal** *by Ryan J. Whitlow*
A father uses sarcasm and humor to appeal a claim rejected by his insurance company.
- 34 Baby Girl** *by Geraldine G. Miller*
One family's decision to ignore a doctor's suggestion and raise their daughter with multiple disabilities at home.
- 62 Special Book Excerpt** When Your Child Goes to School After an Injury
- 67 Networking** Policy statement on education reform, multiculturalism and disability and legislative update from the National Parent Network on Disabilities.
- 74 School Bus Safety Dispute**
Federal debate on school bus safety standards for students with disabilities.



Page 30



Special Mobility Section

DEPARTMENTS

- 6 Family Support** Letters to the Editors, Parents Search, Parents Respond
- 14 Editorial** Investing in All Children
- 38 Resource Section** A state-by-state list of accessibility offices.
- 64 From the Bookshelf** Working Toward A Balance in Our Lives: A Booklet for Families of Children with Disabilities and Special Health Care Needs
- 72 What's Happening** National hearing aid bank, neuromuscular disease referral prog., U.S. Society for Augmentative and Alternative Comm. & more!
- 79 Technology Bulletin Board** ATA Scrapbook of Success.
- 80 Family Life** Family stress from parent-professional conferences.
- 90 Tips for Parents** A personal beeper can buy parents peace of mind.
- 91 Fun Stuff** *by Alice Wershing* Knocking down blocks with Knock-Out.TM
- 92 Family Album** *by Jennifer Schultz* My Sister and I



Page 34

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It was thrilling to watch and listen to young Anastasia Somosa ask President Clinton on national television why her twin sister could not join her in class, even though her sister's disabilities are more severe. We are honored to have Anastasia and her friend, the president, on our cover. Anastasia's advocacy for herself and her sister illustrates how our world has changed while also documenting how much more needs to be done. Congratulations Anastasia — we are very proud of you. And keep after that friend of yours! We thank ABC-TV and photographer Steve Fenn for generously providing the cover photo.



Stanley D. Klein



Maxwell J. Schleifer

Annual Mobility Guide. Beginning in 1990, each March issue has featured our Annual Mobility Guide. The two happy children on the cover of the Guide, Nicole Joaquin and Sean Moore, are participants in Winners on Wheels, a national nonprofit organization which develops community-based chapters focused on empowering youth who utilize wheelchairs. (For more information, call the WOW National Office, (209) 292-2171, ext. 1730.)

Within the Guide, we honor *Family Hall of Fame* inductee Jan Little, an individual who continues to play a major role in the development and evaluation of adaptive equipment. While Little's article, *Finishing the Race*, includes practical suggestions for parents, Ryan Whitlow's *Insurance Claim Letter* illustrates with humor (under stress) the frustrations many parents may face.

Readers Respond to Article. We have heard from many readers who were troubled by *Profound Truths*, an article in our February issue about a family's decision to enroll their son in a residential program. Since *Exceptional Parent* began publication in 1971, we have included articles about both the pros and cons of the delicate decisions parents make because we respect the right of all parents — the most informed experts about their children — to make their own choices. In this issue, Geraldine Miller describes her family's commitment to a different path in *Baby Girl*.

Corporate Accessibility Awards

As more and more business establishments become accessible due to the Americans with Disabilities Act, we invite readers to tell us which companies are doing the best job of offering new and improved services for individuals with disabilities. We are looking for national chains of department stores, restaurants, transportation systems and entertainment/recreation providers that meet the ADA's accessibility requirements. To nominate a noteworthy company, submit a 500-word essay detailing services provided, how long they have been available and the impact they have had on your family. Send your nominations to: Corporate Awards, Editorial Dept., *Exceptional Parent*, 1170 Commonwealth Ave., Boston, MA 02134-4646.

INDEX TO SPECIAL ADVERTISING SECTIONS

SECTION	PAGE #'S	SECTION	PAGE #'S
Mobility Buyers' Guide	59, 60	Marketplace/Advertisers Index	66
Van Conversion Dealers Guide	61	Product Showcase	78
Media Buyers' Guide	63	Schools, Camps & Res. Guide	86, 88

Exceptional Parent

PARENTING YOUR CHILD WITH A DISABILITY

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- 1989 - National Media Award - National Down Syndrome Congress
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Letters to the Editors

Mobility Issue Corrects Mistaken Purchase

I want to thank you for your most interesting and informative magazine. The *Family Support* section, as well as the special issues, have been most helpful.

Upon receiving my first issue in March 1992, I learned that I had purchased a chair that would not accommodate my child to the weight that I had been told it would. I may not have realized this mistake had I not read your magazine. I have recently received the correct chair because the mistake was clear to all concerned. Thank you.

B.D.
Kentucky

Article Didn't Belong in Exceptional Parent

Not celebrating your child's birthday at such an early age because of his misfortunes, as described by Mrs. Fagley (*Profound Truths*, February 1993), is very sad. Whatever has been and will be accomplished for Evan could have been done at home with much more satisfaction.

We don't condemn the Fagleys for the decision they've made, but we feel this article did not belong in *Exceptional Parent* magazine.

Our son is five years old and is severely handicapped. He can't hold his head up, he looks straight past us with his stares and, yes, he takes up a lot of our time. Little things make us happy — his smiles, his laughs and his innocence.

As parents we realize the burdens that come with this situation, but we are rewarded twofold with

the satisfaction that he brings.

Our son has cytomegalovirus retinitis and probably won't progress much in the years to come. God willing, we will stick by his side and receive our little pleasures here and there. Weekend visits just don't cut it for us.

By the way, Bobby will be six years old on May 23 and, yes, he'll be having a party.

B.L. & D.L.
Massachusetts

Chromosome Deletion Support Group

We are a group of mothers of children who have different chromosome deletions. We would like to educate ourselves and the medical community on how best to understand our precious children.

We are from various parts of the country and have established a support group for each other. Anyone interested can write us for more information about our newly formed support group: Chromosome Deletion Outreach, P.O. Box 164, Holtsville, N.Y. 11742, (516) 736-6754.

C.D.
New York

Psychiatric Misdiagnosis

My 12-year-old daughter was an honor student when she developed viral encephalitis two years ago. She displayed bizarre behavioral symptoms and headaches.

The doctors diagnosed her condition as psychological and she was placed in a psychiatric unit. No physical tests were done. I kept pushing them, but the doctor on her case wouldn't listen and told us this was a long-term psychiatric case.

I decided he was wrong and brought in a neurologist. He examined our daughter who had been in the facility for five days. She was semi-comatose and defecating and urinating in her pants. He told us we needed to transfer her immediately

because there was a definite organic encephalopathy.

She went to Barrows Neurological Center where she went into a coma on a respirator and had to be trached. She remained in a coma for one month, then was hospitalized for six months and in therapy for two months.

Our daughter has progressed beyond our expectations. She is now in special education but in regular classes with support. It was a long, hard struggle, but we persevered. Thank God we were aggressive enough to push through the system. How many children are placed in psychiatric units when they need a medical facility?

I don't want any other family to go through the horrible pain that our family has endured.

G.B.
Arizona

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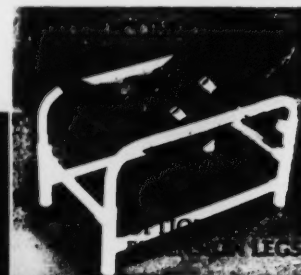


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Parents Search

Alstrom Syndrome

I am the mother of three children. About four years ago, my two younger children were diagnosed with Alstrom syndrome, a very rare genetic condition involving blindness, deafness, obesity, diabetes and various other metabolic disorders.

A tedious 10-year process led to that diagnosis. The long delay was caused by the nature of the condition. Only a vision loss is present at birth; obesity starts in infancy; and hearing loss usually begins after age 10. It was at this point that Alstrom syndrome was suspected.

Numerous blood tests which indicated severe insulin resistance and glucose intolerance confirmed Alstrom syndrome. They do not yet have diabetes, but it is expected to occur in their late teens or early 20s.

This syndrome closely resembles Laurence-Moon Bardet-Biedl syndrome. However, there is no mental retardation with Alstrom. These children are extremely photophobic — they cannot tolerate bright light.

I am in contact with four other families, three from Canada and one from Australia. We started a newsletter to keep each other informed about our children, but I am eager to find families a little closer to home. I would like to hear from anyone with a child with this condition or anyone who suspects their child may have this. I would also be happy to send our latest newsletter (Alstrom Syndrome Newsletter, 1006 Howard Rd., Warminster, PA 18974).

J.M.S.
Pennsylvania

Toriello-Carey Syndrome

Our daughter Allison has recently been diagnosed with Toriello-Carey syndrome, an autosomal recessive gene disorder.

Allison has a tracheotomy and button for feeding. She is also extremely developmentally delayed and has many congenital defects and

severe respiratory problems.

Despite all of her problems, she is a very happy and social little girl. No one has much information on this rare syndrome, not even the National Organization on Rare Disorders (NORD). If there is anyone who has or knows of a child with Toriello-Carey syndrome, we would love to talk with you.

S.P. & D.P.
Illinois

Brachial Plexus Injury

Our 14-month-old daughter sustained a brachial plexus injury at birth and has severely limited use of her left arm. She had nerve graft surgery at 10 months of age to attempt to correct some of the damage. It is taking her a long time to recover the limited function she had before the surgery. We are interested in hearing from anyone whose child sustained a brachial plexus injury.

E.B.
Massachusetts

Chromosome Deletion and Vomiting Cycles

Our nine-year-old daughter has a deletion of bands 21-31 in the short arm of her #1 chromosome. She has speech, language and motor disabilities as well as learning disabilities, social difficulties and an attention deficit disorder. Her IQ is in the average range and she does fairly well academically. She also has precocious puberty which is currently arrested with the use of medication.

In addition to all of this she has cycles of vomiting which began when she was 18 months old. She can go several months without vomiting but during a cycle she may vomit several times a day. No one has been able to medically treat the vomiting. The best we can do is help her manage it (not vomit publicly), but because of her other disabilities, this has been very difficult. There is no real pattern to the vomiting except that it

F.Y.I.

An Overview of Hereditary Ataxia

The hereditary ataxias are a group of neurological diseases classified within the general category of spinocerebellar ataxia. They are characterized by nerve cell degeneration primarily in the spinal cord and cerebellum, the brain coordination center. They are defined as the degeneration of nerves in the brain or spinal cord. As a complex group of diseases, hereditary ataxia is comprised of many different forms of ataxia, all demonstrating lack of coordination or muscle control. Hereditary ataxia is passed on from generation to generation through genetic transfer.

Classification of the ataxias has been difficult and elusive because of the lack of knowledge of the biochemical problem underlying these disorders as well as the uncertainty of the location of the ataxia-causing gene on the chromosome. The complex nature of the disease hampers the ability to give an early diagnosis of the disease.

Of all of the ataxias, more is known about Friedreich's ataxia than any other form of hereditary ataxia. It is caused by an abnormal gene and current research efforts are directed to isolating the actual gene.

It has been estimated that one in 50,000 people in the U.S. have Friedreich's ataxia with one in 100 people cited as carriers of the disease. Males and females are equally affected.

Typical Friedreich's ataxia usually appears before age 20, with an average range of four years to 16 years of age. Onset of the disease may not be recognized for months or years — the child is thought to be "just clumsy." The most common initial symptom is unsteadiness and the second is generalized clumsiness. Other possible early symptoms are scoliosis, weakness of legs with difficulty walking, speech disturbance, nystagmus, cardiomyopathy, areflexia and decreased vibratory sense.

There is progression of ataxia in all extremities without the hope of remission. Studies indicate that ataxia is always present in all four limbs.

Diagnostic procedures include: a detailed family history; a thorough neurological exam; magnetic resonance imaging (MRI); nerve conduction studies; pattern electroretinogram (PERG); and visual evoked potentials (VEP).

At the present time, there is no specific treatment that will affect the course of the disease.

Resource: *Hereditary Ataxia — Fact Sheet* was produced by the National Ataxia Foundation. This excerpt was reprinted with permission from the National Ataxia Foundation, 750 Twelve Oaks Center, 15500 Wayzata Blvd., Wayzata, MN 55391, (612) 333-6621.

continued on page 10

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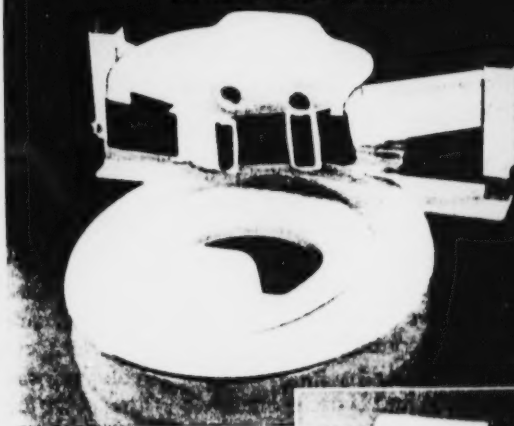
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COLUMBIA

continued from page 8

seems to be worse when she drinks water as opposed to milk or juice.

I would like to hear from anyone regarding the genetic disorder or the recurrent vomiting.

L.B.
Illinois

Spina Bifida and Continence

My husband and I would like to help our four-year-old son with spina bifida achieve continence. Colin is a bright, happy and strong-willed child with normal intelligence and good verbal skills. His lesion is quite low (S1) and he has good neurological function except for pronounced weakness in his ankles and feet. He wears MAFOs and uses forearm crutches.

We believe that Colin has the potential to be continent because he frequently remains dry for several hours at a time and is occasionally dry overnight. He urinates in a stream without dribbling and seems to have adequate sensation. (The few times he was catheterized were very painful for him.)

We also believe that his bowel functioning is good because he has regular bowel movements with no soiling in between. He also exhibits an "anal wink" which we have been told is a good sign.

Despite all of this, efforts to help Colin learn to use the potty have been unsuccessful. This is our second attempt and for the past month we have been using timed potty sittings (about every three hours) with a sticker reward if he is successful and no punishment if he is not.

We don't seem to be getting anywhere, however, and our doctor says that the next step would probably be to use a mild laxative to schedule his bowel movements and begin clean, intermittent catheterization to achieve urinary continence. We are reluctant to do this because of the discomfort involved.

We would like to hear more about alternatives such as

biofeedback and electrical stimulation. We would like to hear from people who have had experience in this area.

Also, our doctor has told us that it is rare for a person with spina bifida, even with low-level lesion, to achieve continence without catheterization, laxatives, etc.

We would love to hear from families in situations like ours. We need to know whether our goals for Colin are realistic.

E.D. & J.D.
Pennsylvania

Editors' Note: Please see *Coping With Incontinence*, February 1993.

Rhizotomy Candidate?

My six-year-old son has cerebral palsy with spastic quadriplegia. Recently his doctor suggested that he may be a candidate for a rhizotomy (a surgical cutting of the spinal nerve roots performed to relieve pain) sometime in the future.

I would like to hear from any parents who know about this procedure and/or have a child who has undergone the procedure.

K.L.
Massachusetts

Hypotonia and Behavior Problems

We are the parents of a 28-month-old boy who was born with multiple disabilities. We have been to many hospitals and doctors to obtain a diagnosis to no avail. Brady is hypotonic in all extremities. He does not talk but he sort of babbles. He picked up about 45 signs which he can do with a little prompting. In his latest developmental testing, he ranged right under 60 percent.

Brady has been a difficult child since birth. He cried most of his first 18 months. Feeding him is also a big concern. He still eats strained baby foods and drinks formula from a bottle. He has some autistic-like tendencies. He doesn't like to be held and likes a routine. He is tactile defective, especially in the face.

However, the hardest thing to

deal with is his behavior. He is still irritable. He is hyper and always on the move but not with any purpose. He doesn't get interested in toys and does not play with any purpose. He is very object-oriented and wants everything in sight. But once he has it, he loses interest right away.

He is aggressive with objects and people. You can't let him be around other children without standing right near him. I do believe he understands what "no" means, but it makes no impression on him.

My day is spent on the floor with him, trying to engage him in some sort of limited activity. Television and books are like the toys — he does not care about them. He walks, but because of his ataxia, he falls a lot.

Please contact me if this sounds familiar to any parent out there. Maybe you have found a way to deal with your child and can pass that information on to me.

M.B.
Florida

Large-size Diapers

Our two-year-old son, Jonathan, has lissencephaly. He is a big boy and has outgrown standard diapers. I have had no luck in finding an alternative diaper that will keep him dry through the night. He always wakes up cold and wet.

I have called two major diaper companies and one of them informed me that if enough interest in a larger size diaper was shown then they would make one. If anyone shares my problem or has found a better diaper, please contact me.

L.B.
Maine

Undiagnosed

Our 10-year-old son Jacques is very hyperactive at times. He was born full-term following a normal pregnancy. I first noticed that his eyes did not follow objects in front of him, then we were told that he has low muscle tone and global developmental delay.

We have taken him to several neurologists in search of some answers and a diagnosis. His EEG and MRI were normal but at a slower pace than his chronological age. He is still unable to feed himself, dress and undress or go to the toilet by himself. He does not chew his food with his teeth but rather with his tongue. He has had behavior problems for the past two years, and they are getting worse as he gets older.

We would like to hear from other parents with a similar child. We also would like to find out if there are any support groups for parents of children with similar disabilities.

*J.M. & A.M.
California*

G-tube Insertion and Daily Gagging Episodes

We have a three-year-old adopted daughter who has cerebral palsy and diabetes insipidus. When Rebekah came to us at 10 months of age, she already had several hospitalizations due to projectile vomiting and resulting dehydration.

The first year with us followed the same pattern. For periods of four to five weeks she would be fine, taking bottles and baby food by mouth. Then she would get lethargic and sick, refuse anything by mouth and spend a few days in the hospital.

In July 1991, the doctors decided to perform a Nissen and insert a G-tube. The Nissen was to keep her from vomiting, but three days after surgery she started gagging like she was trying to clear her throat. She has been gagging every day since.

In the morning it wakes her up and she usually brings up phlegm. She usually has a couple of episodes during the day and brings up formula. We have tried different formulas, medications and rates per hour on the feeding pump but nothing has helped. No one seems to be able to find a reason for the gagging. She has also shown no interest in taking

anything by mouth since the surgery.

Has anyone had this problem with their child and found relief? It is uncomfortable for her and irritating to her throat. We'd like to find an answer before she tears out the Nissen and has to have surgery again.

*D.B.
Ohio*

Fun Center for Teens

I am the mother of 16-year-old twin daughters who have cerebral

palsy. They use wheelchairs and have normal speech and intellect.

The years have been rough on the three of us. I have raised them alone and seen them through many surgeries. Now that they are teenagers, their psychological pain has increased drastically. They see friends going places, doing things and, of course, dating.

I am currently trying to obtain a grant to build a teen recreational

continued on page 87

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Parents Respond

Parent Seeks Support Following Child's Death

Response to T.W.'s Letter to the Editors, November/December 1992.

Our three-year-old daughter who had multiple physical, developmental and medical problems died unexpectedly in her sleep May 3, 1991. The May issue of *Exceptional Parent* arrived the day before we buried Lindsay. I will never forget the confused and upsetting feelings I had when it arrived.

Being the parent of a very special child was my life. I had always had so much support — through friends, family, the magazine, families and professionals met through various schools, programs and medically related experiences. I missed the community our daughter's life gave me. My journey through the past 19 months has mostly been accomplished alone, but I have slowly found help along the way and have come to realize that not only have I not lost my old community, I have also gained a new one.

Like you, I have always been interested in finding a support group for people like us. I have never gone to a Compassionate Friends (CF) monthly meeting, but I did go to the national conference in Charlotte, N.C., last July. My hope was to meet parents who had lost a special child. I felt they would be the only ones who could really understand.

I exchanged notes and now correspond with parents of a six-year-old girl who had several of Lindsay's conditions and had basically died the same way. I met quite a few people with whom I continue to correspond after sharing feelings at the conference workshops. There are quite a few people like us out there, and all of them expressed the same interest to meet other families who have lost a special child. Because I attended the conference, I now have several friends who have also lost a child.

All of us who found each other

at the conference were disappointed that CF does not offer a workshop for parents who have lost a child with disabilities. I wrote to the national headquarters to suggest a workshop, and they told me many people have asked for the same thing and they are working on it.

I definitely believe that parents who have suffered the loss of a child with disabilities have a very special set of circumstances, feelings and problems to deal with. Perhaps one day a group of us can be organized into a support group.

K.F.D.
Virginia

Placement Decision

Response to G.H. & R.H.'s Parents Search, November/December 1992.

Our 13-year-old son also has multiple disabilities — moderate mental retardation, fine motor problems, speech delay and severe behavioral problems with hyperactivity (ADD).

For the last five years he has been on 16 pills a day to control his hyperactivity and behavior. We were on the waiting list for residential placement for the last two years. This was not a tough decision because the waiting list was so long that realistically we did not think a spot would become available.

This past July, an opening occurred in a group home an hour-and-a-half away. It's a beautiful facility in a small city with a loving staff. It has truly been a miracle. The first two months were difficult. We had a very empty feeling and went through a number of different emotional reactions — hurt, shame, anger, guilt, sadness. I was putting one foot in front of the other to get through the day. Counseling for my wife and oldest daughter is ongoing.

Our son adjusted quickly. He is the healthiest and happiest he's ever been. These professionals have 16 boys, and they take care of them with set schedules and boundaries.

Our family is once again thriving whereas before we spent months (during bad times) solely focusing on our son. Now he has two homes — the group home (with friends he never had before) and his home with us. He comes home for occasional weekends and holidays. He was sad at first, but now he is packed up at the end of a weekend and ready to get back into his routine.

J.S.
Florida

Eating Problems

Response to T.S.'s Parents Search, October 1992.

My three-year-old son has cerebral palsy and had many of the same eating and drinking problems you described. He is still not able to eat everything, but we did stumble upon something that helped him learn to drink from a cup.

Andrew has always loved the smooth kind of yogurt, and after it is stirred a bit, it gets even thinner. We held the yogurt cup to his mouth and carefully let him "drink it." Because it was thicker than other liquids, it didn't run down his throat and cause him to gag. This also worked with other foods of similar consistencies such as applesauce, baby food and creamed cereals.

It helped him get the hang of using the mouth muscles necessary to drink. He also enjoyed hearing the echo of his "smacking" in the cup and got to the point where he protested being fed yogurt any other way. We noticed a remarkable improvement in his ability to manage water from a cup. We never had a chance to consult a therapist about using this approach, so I don't know if there are any drawbacks to it. Andrew more or less initiated this himself, and it sure worked for us.

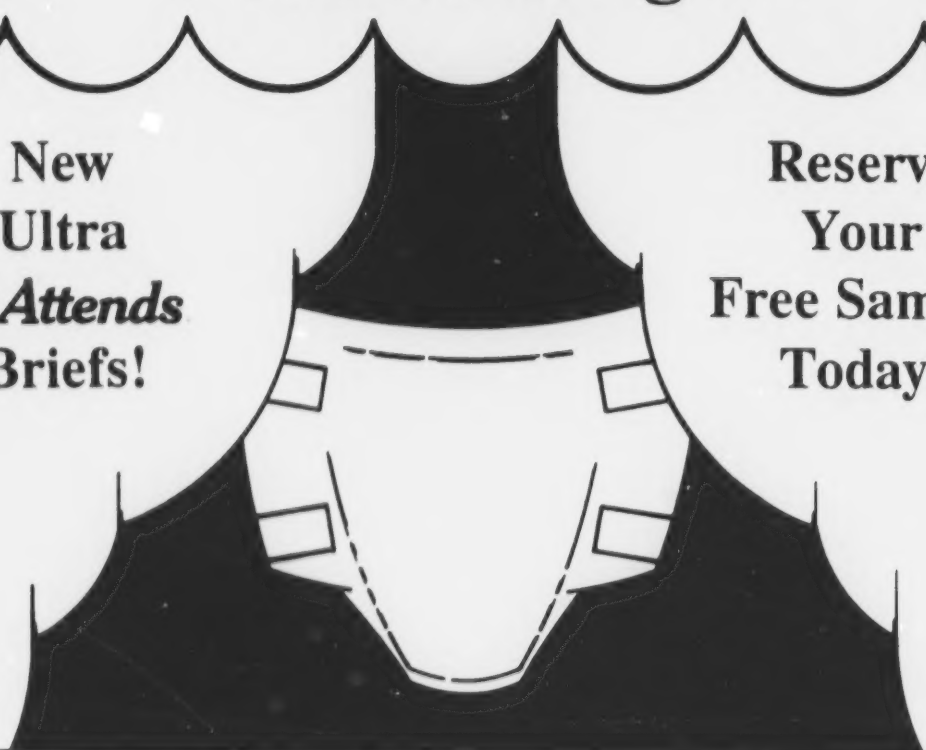
Another thing that helps is a cup that has almost a fourth of one side cut away. This makes it easier for us to see the water level as we tilt the cup for him to drink.

W.R.
Hawaii

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Investing in All Children

In his State of the Union message, President Clinton spoke eloquently about a new direction, a focus on children. "Each day we delay really making a commitment to our children carries a dear cost." Speaking about childhood immunizations, nutrition programs and Head Start, he explained how investments to meet the needs of young children and parents have long-term economic implications. Programs, relatively inexpensive in the short run, save vast sums in the future. A few days later, in a question-and-answer session with children, President Clinton demonstrated his commitment to children and again explained the importance of investing in children and families — not just because such needs deserve to be met, but because it is good fiscal policy.

Unfortunately, far too many citizens do not yet appreciate this perspective and resist the efforts of parents, professionals and other advocates seeking financial support for early intervention, family support and other health and education programs. Examined from only a short-term perspective, programs may appear expensive and "results" limited. For example, early intervention programs do not usually result in dramatic, "noticeable" improvements in a year or two. Rather, the enduring value of the investment becomes evident when children and families are followed through years of appropriate programs. Children are progressing far beyond expectations and many are no longer experiencing complicated and costly educational or health problems.

With our president leading the way, parents and professionals have an opportunity to show the value of specific investments in programs for children with disabilities and counteract the voices of the naysayers unable or unwilling to assume a long-term perspective. For example, state governments no longer spend millions of taxpayer dollars on institutional care for most infants and young children with disabilities. In the past, even in institutions that provided therapeutic services, young residents were not expected to improve. Instead, institutions were one-way tickets to nowhere financed by taxpayers. For those children with disabilities who did remain at home, expectations were minimal and parents were expected to single-handedly provide for all needs. Although direct taxpayer costs decreased, neither children nor parents prospered and there were vast indirect costs to families as a result of careers unfulfilled, other life goals put aside and/or the costs of caring for parents' own health problems caused by the stresses of

parenting in isolation.

Today, most young children with disabilities grow up at home and receive specific services that enable them to participate in educational, recreational, religious and social life alongside peers. But explaining these historic changes may be too vague for present-minded citizens fearful of increased taxes. Instead, like our president, we must present specific details. Mobility equipment (the focus of this issue) is an illustration of the need for a long-term perspective. Today's wide selection of mobility products includes wonderful advances in technology and colorful styles — different sizes and types, designed for active lifestyles — a striking contrast to the days when all wheelchairs looked the same! Most were big; a few were small. All were dreary and designed to serve the needs of passive, seated "victims," who occasionally moved short distances indoors. Many people sat uncomfortably, leaning to one side or another or sliding forward — gradually developing added aches, pains and dangerous pressure sores.

Children who need mobility equipment can enjoy life...
and plan for a future as independent taxpayers.

Today, parents of a child with a physical disability learn early that proper positioning facilitates the child's active participation in everyday life while providing protection from serious health problems caused by poor posture and inactivity. Today, most children who need mobility equipment can enjoy life alongside neighborhood peers as active participants in community life and plan for a future as independent taxpayers! Nonetheless, when parents seek the funding to which they are entitled — from private insurance or governmental programs — to purchase mobility equipment and other assistive technology devices, they are often forced to accept the least expensive alternative such as a generic wheelchair without the benefits of new positioning technologies and materials. To save a relatively small amount in the short run, a child faces a downward spiral of decreased opportunities and increased health risks.

We welcome our new president's perspective on the needs of children and families and his pledge to bring about major improvements in our health-care system. As the complex process of getting to the details evolves, parents of children with disabilities and their allies must be ready to educate the public about investing in not just their children, but *all* children.

— S.D.K. & M.J.S. —

Exceptional Parent

PARENTING YOUR CHILD WITH A DISABILITY

Annual Mobility Guide

*for Parents of Children
and Adolescents*

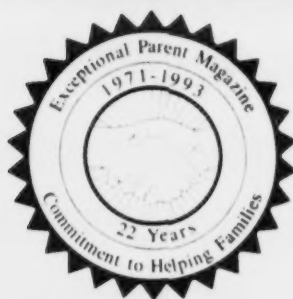


Introduction

WELCOME TO THE 4TH Annual Mobility Guide. Every March since 1990, we have presented articles and advertisements emphasizing mobility solutions to meet the needs of many children with disabilities. Each year, as more and more children with disabilities are enjoying opportunities to participate in a growing range of indoor and outdoor activities, creative designers and manufacturers are responding with innovative technological changes in existing products as well as exciting new products. To enable parents, professionals and children to learn about a wide range of products, this year we have provided a variety of ways for products to be displayed.

The articles within the Guide focus on the many challenges and frustrations families face when trying to find funding for equipment.

Photo by Keith Seaman, courtesy of Winners on Wheels



Finishing the Race

by Jan Little

Jan Little is director of Infini-tec in Chicago, Ill. Infini-tec is an information, training and research facility developed to increase access to assistive technology for people who need it. Little has developed assistive technology, marketed it, improved its service delivery, conducted workshops and uses it herself. Little earned her bachelor's and master's degrees in journalism and communications sciences from the University of Illinois/ Urbana-Champaign.

It was with some surprise that I learned I had been selected for membership in *Exceptional Parent's Hall of Fame*. Being a parent is the only thing I haven't experienced, despite being quadriplegic since a bout with polio in my early childhood.

At first, I considered politely declining because it's not possible to know what it's like to be the parent of a child with a disability unless you've been one. Upon reflection, however, I realized that I may have a message of interest to parents because I was a child who grew up with a severe disability. My parents, like today's exceptional parents, were pioneers. Like you, they fought an obstacle course — except back then, there weren't even paths on which to run and the woods were full of hostile elements.

Nearly 40 years ago, my parents were told that I would always be a hopeless cripple. They were advised to keep me at home, or put me in one, and get on with their lives. Like you readers of *Exceptional Parent* understand, that attitude was not acceptable to my parents.

All education was denied to me from the eighth grade until my junior year in high school. Friends and neighbors tutored me and I was able to go on to college and earn two degrees. Our community accepted me when I was a child. I participated in 4-H, the farm youth training ground. My family, tutors and neighbors demanded as much of me as of any other child. Later, my professors and employers demanded performance equal to that of my peers.

The one gift you can give your child with a disability is to expect and demand the very best from him or her. It's frequently easier for you to dress your child or get him or her a drink, but you may be depriving your child of the joy of independence and equality.

The demands made on me for performance equal to my peers have had other rewards. I have enjoyed a career in business, triumph in international sports, the opportunity to promote legislation for access to assistive technology and equal opportunity and the honor of having been chosen by United Cerebral Palsy of Greater Chicago to guide the development of Infini-tec.

This center will involve the efforts of many people in using technology to overcome limitations resulting from disabilities.

Infini-tec will serve as a national model and resource for parents, people with disabilities, health care professionals, manufacturers of technology and perhaps most importantly, the people who fund technology to overcome disability.

Now, let me summarize why parents of exceptional children are like the marathon runners who have completed 25.5 miles of a 26-mile, 385-yard race.

The marathon is about making sure that every child — whether he or she has a mobility limitation, a cognitive problem, a learning disorder or a sight or hearing impairment — has the opportunity to be a fully empowered member of our society.

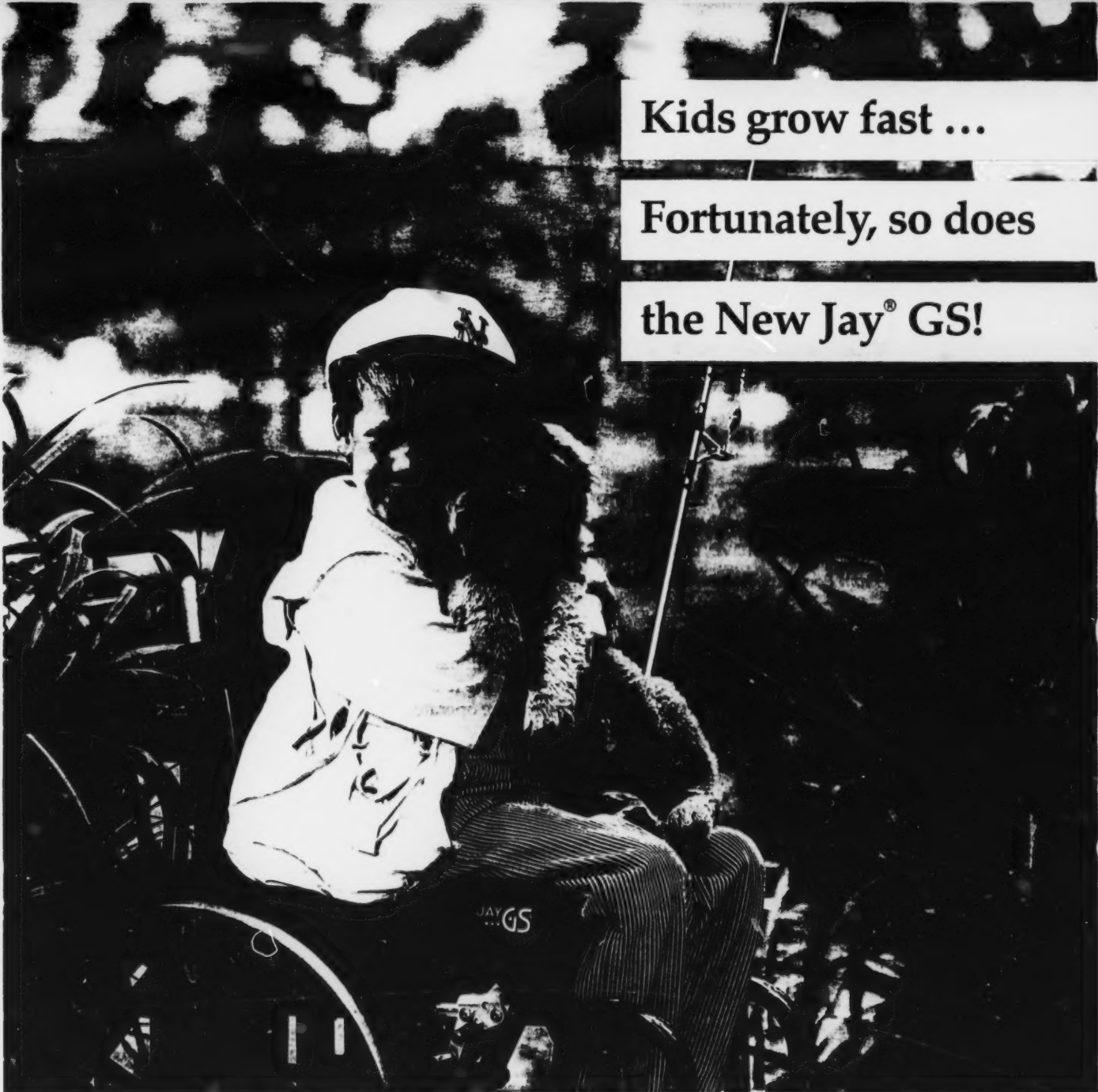
In the past 20 years, parents have:

- Forced legislation assuring every child the opportunity for an equal and integrated education.
- Promoted legislation to give children with disabilities access to the technology that can give them a level playing field.
- Been an important factor in the passage of the Americans with Disabilities Act, the most sweeping civil rights legislation ever enacted by any nation.
- Agonized over the lack of support from their communities but drawn strength from other parents in similar situations.
- Known the despair of trying to assure the rights of their children but have been too stubborn to give up.

The most important event that has affected the lives of those of us who have disabilities in the past 20 years has not been legislation. It has not been the proliferation of technology. It has not even been the public's change of attitude that says, "Hey, people with disabilities are valuable people, too." The most important event has been seeing the courage of parents, including my own, who have said, "I will not accept that my child must be a second-class citizen because he or she has a disability."

Every mile you have run has made life easier not only for children with disabilities, but also for adults who become disabled and those of us who will be fortunate enough to enjoy advanced age without physical and mental restrictions.

You have blisters on your feet, you've "hit the wall," you are weary. But what a sweet victory — what a contribution to our entire society exceptional parents have made.



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Finding Funding for Assistive Technology



The term "assistive technology device" means any item, piece of equipment or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities.

— From Section 3. Technology-Related Assistance for Individuals with Disabilities Act of 1988

New technological developments have raised the expectation that people with disabilities can employ assistive devices to function more independently in their homes and communities and pursue vocational goals not dreamed of before. Every day people act on this expectation and do gain more independence.

But expectations are often dashed or delayed when people seek financial assistance to purchase devices and are faced with a maze of funding sources, eligibility restrictions, paperwork requirements and rules and regulations governing the funding of such equipment.

Selecting Funding Resources

Sources of financial assistance for purchasing assistive technology are many and varied. Each has a different eligibility criteria. Most require that an application for services or financial assistance be completed. All have specific rules regarding what equipment can be purchased.

Most primary sources of financial assistance are programs authorized and funded by the federal government. Programs such as Social

Security are operated by federal agencies. Others, such as vocational rehabilitation programs, are federal/state partnerships and are operated by state agencies.

The Supported Employment (Title VI programs) and Independent Living Services (Title VIIA & VIIC programs) are federal/state rehabilitation programs that also provide funding for assistive technology. Independent living programs are noteworthy because they can provide funds to purchase assistive technology for individuals neither working nor preparing to work, and who are therefore ineligible for vocational rehabilitation. Title VII monies can pay for assistive devices that enhance an individual's ability to function more independently at home and in the community.

In addition to government agencies, some private organizations can be sources of funding. Foundations, corporations and trust funds are potential sources of direct financial assistance. Some research at a local library will help identify an appropriate source of funding. Usually, the person seeking the funds must write a funding proposal or justification statement indicating the nature of the need and how the

monies will be spent. The proposal may be simply a letter or may require more formal correspondence.

Civic organizations and service clubs are another resource. They often raise funds on behalf of individuals needing financial assistance to purchase of assistive devices. Lions Clubs, Kiwanis, Rotary and Pilot International are examples of organizations that have a history of assisting people with disabilities.

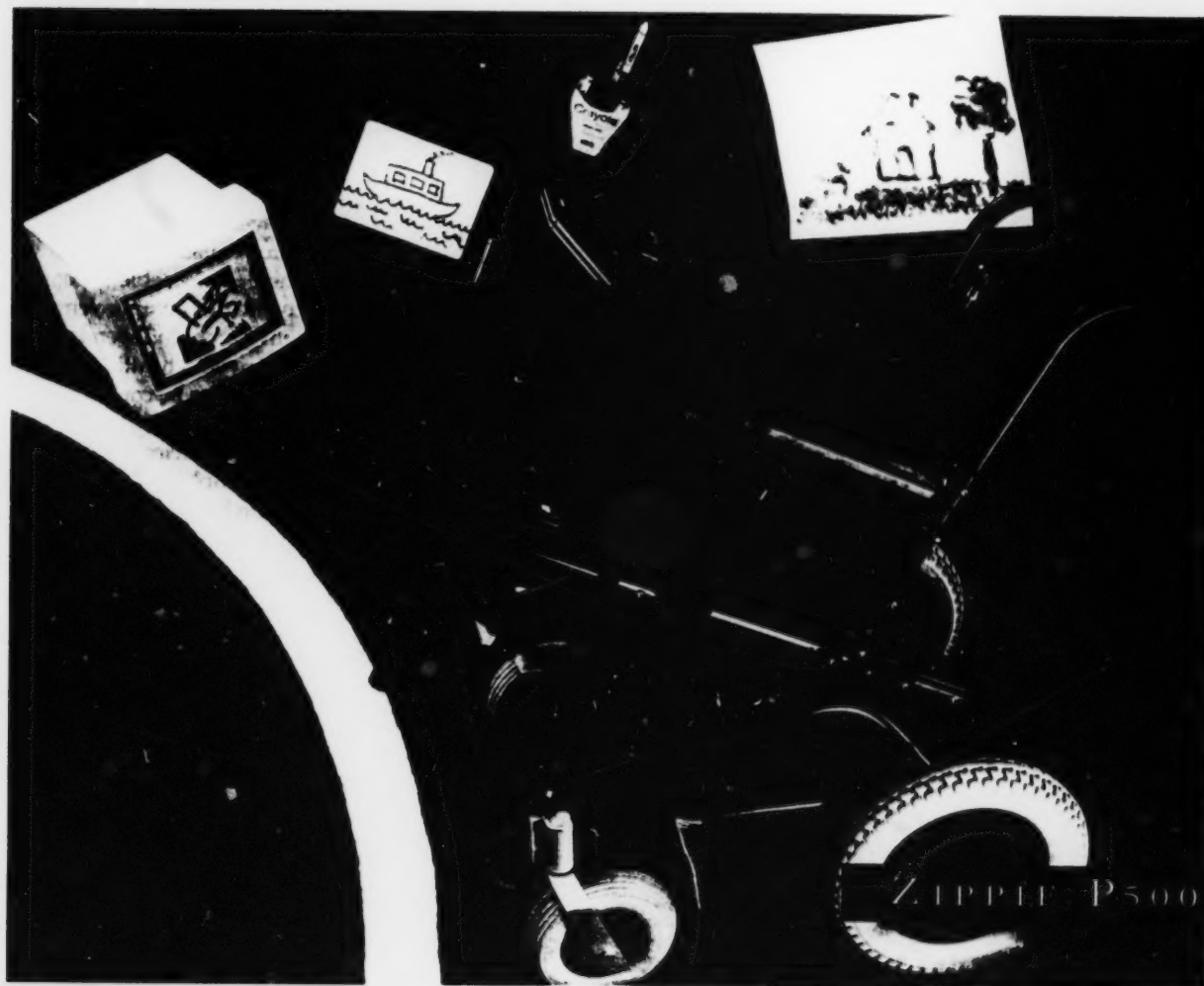
Finally, there are several organizations that have established low-interest revolving loan programs. These programs are particularly valuable to individuals and families whose incomes make them ineligible for programs based on financial need. The low-interest loan program administered by the National Easter Seals Society was established specifically to aid people with the purchase of assistive technology. The American Foundation for the Blind, in cooperation with the Xerox Corporation and the Bank of Boston, established a low-interest loan program to help people who are blind to purchase personal readers.

A few manufacturers of assistive technologies provide financing or other forms of time payments, but this is a rare practice. However, often

continued on page 20

Zippe TS photo courtesy of Quicke Designs.

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Foster Parent &
Registered Nurse*

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maneuverable.
And Andrea loves
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manufacturers and vendors are sensitive to the difficulties consumers face when trying to find funding sources. Prentke Romich, Co. of Wooster, Ohio, is one example of a vendor attempting to aid its current and potential customers by educating them about the funding process (see page 36).

Once you have identified a primary source of funding, you should develop a specific strategy that is tailored to your unique requirements.

Developing a Funding Strategy

When deciding on the best approach for funding the purchase of assistive technology, it may be appropriate to choose one primary source. However, funding sources often like to share the cost with one or more other providers. The key to success is selecting the appropriate funding strategy.

The Arkansas Research and Training Center offers the following questions which might help to narrow down the choices:

- What is the most promising funding source?
- Has this source been dealt with before?
 - a. Was it successful?
 - b. What problems were encountered?
 - c. Who was the contact person?
- Is there a possibility of more than one funding source?
- Will the vendor be an advocate and provide preapproval and billing services?
- Are there persons with disabilities using these devices, and can they be contacted for suggestions on their proper use?
- Will the device enable the consumer to enter or continue employment, live more independently or improve overall health? Can the funding source be convinced of this advantage?
- Are written policies of the primary source available?
- If a person has a disability as a result of a job-related accident, is the device the responsibility of workers' compensation insurance?
- Will a civic or charitable organization, foundation or association help raise the necessary funds?

The Arkansas RTC publication notes that the answers to these questions will be unique for each individual and may depend on factors such as severity of disability, age, education, employment status, insurance coverage, and geographical location.

Preparing a Justification Statement

Some funding sources require the applicant to prepare a justification statement. This is particularly true for government programs. When the funding source is a public or private insurance policy, a statement must be submitted by the expected beneficiary, a physician or a therapist indicating the medical necessity of the purchase.

When applying for funds from a state vocational rehabilitation agency, the applicant must demonstrate that the device will assist in preparing for, getting or keeping a job. If work is not an expected outcome, then the justification must indicate

continued on page 23

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- sources of funding which may be able to provide assistance in addition to the amount you receive from the Mobility Motoring Program.

¹ Ford Motor Company will authorize the selling Ford or Lincoln-Mercury dealer to pay the vehicle purchaser an amount equal to the cost of vehicle adaptive equipment conversion, up to a maximum of \$750.

² Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of purchase or lease. Ask your Dealer for complete cellular phone details.

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Tech Act State Projects

The Technology-Related Assistance for Individuals with Disabilities Act of 1988 P.L. 100-407, commonly known as the Tech Act, authorizes the U.S. Department of Education to provide grants on a competitive basis, to establish and operate consumer-responsive, state-wide programs to provide people with disabilities and their families with information about the availability of assistive technology products and services. Forty-two states currently have Tech Act programs. It is hoped that all 50 states and U.S. territories will be funded by 1995.

Some states have used Tech Act money to help people with disabilities actually purchase assistive devices, but this is not the primary purpose of the program. Several of the projects, like the ones in South Carolina, Kentucky, Maryland and Nebraska, have produced funding resource guides specific to their states. Contact RESNA to find out if there is a Tech Act project in your state.

RESNA Technical Assistance Project RESNA

1101 Connecticut Ave. NW
Suite 700
Washington, DC 20036.
(202) 857-1140 (Voice/TTY)
Hours: 9 a.m. to 5 p.m. (EST)

RESNA is an association that works for the advancement of rehabilitation engineering and assistive technologies. It has a federally-funded contract to provide Tech Act projects with technical assistance and information on how to develop and implement programs that allow people with disabilities and their families to receive appropriate assistive technology services. RESNA can provide consumers with information about 42 projects currently funded by the Act; there may be a project in your state. Tech Act programs do not usually provide direct funding for assistive technology.

continued from page 20

the device will enhance the individual's ability to function independently.

Local school districts will often pay for devices and auxiliary aids used in the classroom. Families requesting that the school pay for assistive technology should be prepared to demonstrate how the device will enhance the child's ability to obtain an appropriate education in the least restrictive environment.

Other funding sources will have their own specific requirements.

Success in securing funding is often dependent on the applicant's ability to address each agency's unique requirements in a funding request.

Keys to Funding

In sum, the keys to opening the agency doors and breaking down funding barriers are knowledge, determination and preparation. First, identify specific needs, then identify assistive technology that addresses the need. Become familiar with potential funding sources, their eligibility

continued on page 24

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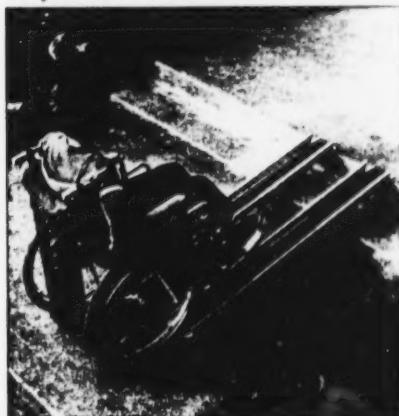
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criteria, paperwork requirements and payment policies. Learn to select appropriate funding sources to match the need and to justify the funding request in terms that meet the agency's goals. (See the chart on page 26 for a list of agencies and organizations that can be of assistance in your search for funds.)

Finding Sources

In seeking funding, parents (in conjunction with their child's clinical and educational teams and an adaptive medical equipment professional) may need to use more than one source in order to obtain the necessary device. As illustrated in the



EZ-ACCESS R-1000 portable ramp.

article *Insurance Claim Appeal* (on page 30 of this issue), applying to any of these funding sources can be a frustrating process. The following list of sources also includes eligibility requirements:

- **Credit financing.** Eligibility is based upon the applicant's credit history. Collateral is usually used to secure the loan along with other assurance of likelihood that the loan will be repaid. Because some equipment can be difficult for a bank to resell in the event of a default, the loan may need to be secured in other ways.

- **Medicaid.** Based on Title XIX of the Social Security Act, Medicaid covers needy persons who are eligible for AFDC or Supplemental Security Income (SSI) programs. Some states cover medically needy

persons whose incomes, after deducting medical expenses, fall below the income threshold.

Medicaid equipment payment policies vary from state to state, generally following Medicare policies. Most states pay for home medical equipment; many pay for prosthetics and orthotics. Augmentative communication equipment is paid for by a growing number of states. "Medical necessity" is the critical factor for payment.

- **Medicare, Part B.** Based on Title XVIII of the Social Security Act, persons under 65 years of age who are disabled severely enough qualify for Social Security Disability Insurance (SSDI) for at least 25 months are eligible. Payments are made for so-called durable medical equipment (DME) which:

- (a) can withstand repeated use;
- (b) is primarily and customarily used to serve a medical purpose;
- (c) generally is not useful to a person in the absence of illness or injury;
- (d) is appropriate for use in the home.

Examples of equipment covered include internal prosthetic devices, external braces and artificial limbs or eyes.

- **TEFRA.** Based on the Tax Equity and Fiscal Responsibility Act of 1982, children (infants through age six) are eligible. TEFRA provides coverage for children deemed diagnostically eligible (as established by SSI definition), but who would be financially ineligible for SSI due to parental income. Children must meet medical necessity requirements for institutional care; however, the intent of this legislation is to provide the necessary services, including equipment, for the child to remain at home.

- **Private Insurance.** Eligibility depends on specific terms of the insurance policy. Often equipment is not explicitly specified in the contract. Payment then depends upon the insurer's legal obligations as well as the role of the desired equipment in meeting the child's needs.

- **Special Education.** Children with disabilities through age 21 are

continued on page 28

Getting Your Facts Straight

Compiling a Personal History for Funding Request Forms

Every funding request will require that you provide basic personal information. It may be helpful to collect this information before approaching potential funding sources.

In addition to information such as your name and address, be prepared to offer the following:

- Primary disability
- Time of onset
- Cause of onset
- Secondary disability(ies)
- Time of onset
- Cause of onset
- Employment history (including length of employment and reason for leaving)
- Names, ages and relationship of dependents
- Family income (amount before taxes)
- Monthly expenses (including rent or mortgage payments, utilities, outstanding loans and medical expenses)
- Health insurance (including plan type and, for people categorized as a dependent, the name of the policy holder).

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Agencies and Organizations

The following agencies and organizations may be of assistance in your search for funding. In some cases, the organizations have national, state and local offices and you will be directed to the office nearest you. Some of the organizations in this listing do not provide funding directly.

Hear Now

4001 S. Magnolia Way
Denver, CO 80237
(800) 648-HEAR
(303) 758-4919 (Voice/TTY)
Hours: 10:30 a.m. to 6 p.m. (EST)

Hear Now is a national non-profit organization dedicated to helping individuals with limited resources who are deaf or hard of hearing. Hear Now disseminates donated, reconditioned behind-the-ear hearing aids or cochlear implants to low-income people with hearing impairments through their National Hearing Aid Bank. There is an application process for acceptance into the program. Hear Now can also make referrals to the caller's local hearing impairment services.

Muscular Dystrophy Association

National Office
3300 E. Sunrise Drive
Tucson, AZ 85718
(800) 572-1717
(602) 529-2000

Ask for the Patient Services Dept.
Hours: 10:30 a.m. to 7 p.m. (EST)

MDA is a national voluntary public health organization that provides assistance to people with neuromuscular diseases through its state and local chapters. MDA is funded almost entirely by individual private contributions. Publications available include MDA's free *Patient Services* brochure, which includes information about their operating procedures, patient services and equipment provided to qualified applicants.

National Easter Seal Society Computer Assisted Technology Services (CATS) Program

70 E. Lake Street
Chicago, IL 60601-5907
(312) 726-6200
Contact person: Bill Watson
Hours: 9:30 a.m. to 6:30 p.m. (EST)

The CATS program provides information on how people with disabilities can obtain loans. The National Easter Seals Office can refer callers to 12 regional CATS programs. Easter Seals can also provide information about getting computers and related computers at a discount. The national office will also refer the caller to local Easter Seal affiliates whenever possible.

The National Information Center for Children and Youth with Disabilities (NICHY)

P.O. Box 1492
Washington, DC 20013
(800) 999-5599
(703) 893-6061/893-8614 (TTY)
Hours: 8:30 a.m. to 5:30 p.m. (EST)

NICHY can refer interested parents to Parent Training Information Projects (PTIPs) and Parent-to-Parent support groups in each state. While they do not provide funding, PTIPs and Parent-to-Parent groups can link parents seeking funding information with each other and, in some cases, can provide information on legal rights pertaining to Individualized Education Plans, as well as parents' potential roles in securing funding for assistive technology.

The Foundation Center

79 Fifth Avenue
New York, NY 10003-3076
(800) 424-9836
Hours: 10 a.m. to 5 p.m. (EST)

The Foundation Center is an independent national service organization established to provide information on philanthropic giving. It publishes directories, such as *Foundation Grants to Individuals*, which you can use to identify funding sources in your area and determine whether you qualify for funding. The Center maintains information in over 180 libraries across the U.S.; the national office can give you information about participating libraries in your area.

United Cerebral Palsy Associations

1522 K Street NW
Suite 1112
Washington, DC 20005
(800) 872-5827
(202) 842-1266 (Voice/TTY)
Hours: 9 a.m. to 5 p.m. (EST)

Through its 150 local affiliates, UCPA assists in work site accommodations, environmental controls, computer access for pre-schoolers, school-age youth and adults, adaptive toys and switches, augmentative communication and other assistive technology. Services offered by affiliates vary; some provide financial assistance and/or equipment loan programs. Contact your local affiliate to determine what type of assistive technology services they offer; local affiliates also provide information and referral for assistive technology services and funding.

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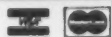
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The Carrie Rover by J.A. Preston.

continued from page 24

eligible based on the Education for All Handicapped Persons Act (P.L. 94-142) and Amendments and Chapter I (Elementary and Special Education Act). Payment for equipment is justified as expediting educational goals of students. This source is also now responsible for meeting the

family support needs of families with preschool-aged children. In many states, equipment is owned by and remains at the student's school.

Information about special education funding is sometimes available from your Local Education Agency (LEA), usually your school district's special education coordinator or your state Board of Education, within the office of the state Director of Special Education Programs. Contacting a local parent advocacy group may also be helpful in this process.

This article has been adapted from ABLE-
DATA Fact Sheet, number 14, July 1992,
entitled *Funding Assistive Technology*.
ABLEDATA is located at the National Rehabilitation Information Center (NARIC). NARIC is a library and information center on disability and rehabilitation. NARIC collects and disseminates the results of federally-funded research projects. The NARIC collection also includes commercially published books,

journal articles and audiovisuals. NARIC manages the REHAB-DATA bibliographic database, which contains citations and descriptions of the material in the collection.

For copies of the fact sheet (single copies are free) or more information, contact ABLE-DATA, 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 227-0216 or (301) 588-9284 or call ABLE INFORM, an electronic BBS, at (301) 589-3563 with the modern settings 2400 baud, 8-N-1.

Both ABLEDATA and NARIC are funded by the National Institute on Disability and Rehabilitation Research (NIDRR), with contracts number HN92026001 and HN90028001, respectively. Both are operated by Macro International, Inc. The Provision of Assistive Technology Services in Rehabilitation by Barry Brandt is the publication of the Arkansas Research & Training Institute referred to in the article. Copies are available for \$12.50 plus \$3 postage and handling from Arkansas Research & Training Center in Vocational Rehabilitation, University of Arkansas at Fayetteville, P.O. Box 1358, Hot Springs, AR 71902, (501) 624-4411, (501) 624-3515 (fax).

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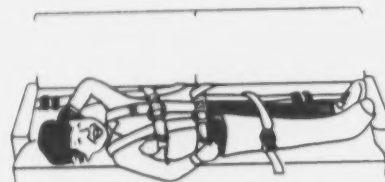
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FAX 1-414-567-4341

CLAIM DENIED

Insured's Name:
Policy #
Date:

Whitlow, Ryan J.
012-34-5678

Insurance Claim Appeal

I started to send this letter "To Whom It May Concern" but was afraid that it might be returned to me with a stamp that reads "No Such Person At This Address." Please consider this correspondence an official appeal to your decision to deny payment of our claim for our daughter, Ashley Ann. The amount of \$587.20 was paid to a local adaptive equipment dealer for an insert that is an integral part of Ashley's wheelchair, stroller, whatever you want to call it.

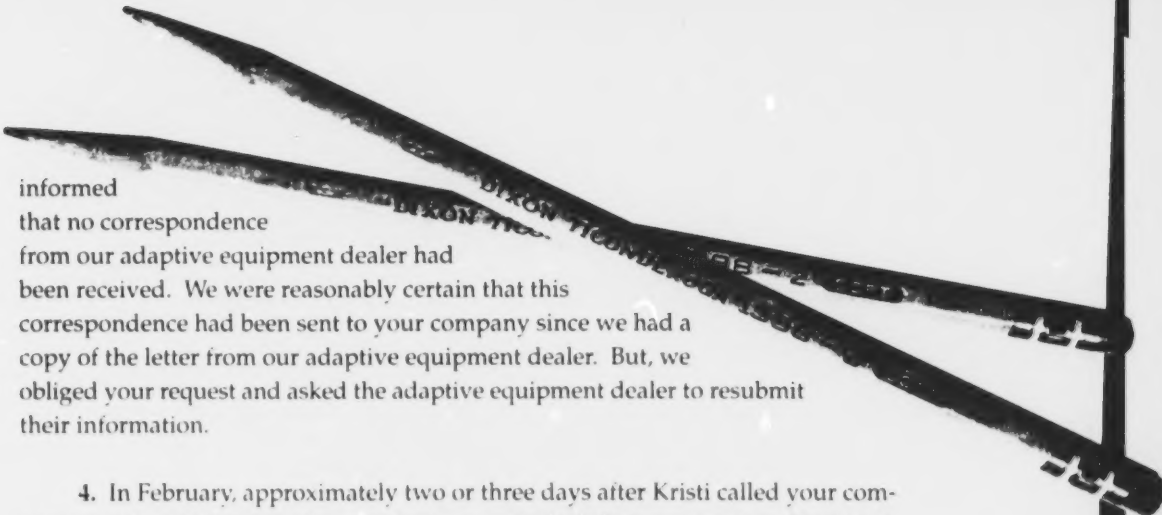
If at all possible, please try to step back from your spreadsheets and printouts and try to see the human side of our story. The following is a brief history of events that have occurred thus far:

1. We submitted the claim for Ashley's seat insert to your company, our insurer.

2. Around Christmas, our adaptive equipment dealer received a letter from your company stating that they needed more information about the insert before the claim would be processed.

3. We received a letter from your company, our insurer, stating that the claim could not be processed because your company was waiting on further information from our adaptive equipment dealer. My wife, Kristi, called your company to follow up and was

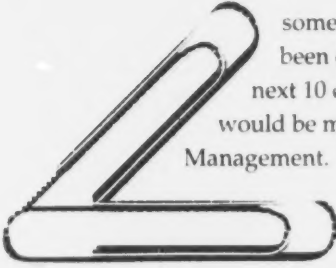




informed
that no correspondence
from our adaptive equipment dealer had
been received. We were reasonably certain that this
correspondence had been sent to your company since we had a
copy of the letter from our adaptive equipment dealer. But, we
obliged your request and asked the adaptive equipment dealer to resubmit
their information.

4. In February, approximately two or three days after Kristi called your company and found that our adaptive equipment dealer's letter was not on file, Kristi called your company again to let you know that a second copy of the letter should be en route. In this conversation, Kristi was told by your company's representative that, "Oh, yes, we have that letter. Your claim has been denied." Pretty fast work. The representative went on to tell Kristi that we would have to appeal this decision if we wanted to pursue the matter further. Kristi asked how the appeals process works. The representative told Kristi that she did not know. (This was the Customer Service department. Keep this in mind for further reference.) The representative went on to say that she would have Someone get back to her. (I'm sure you're familiar with Someone. Someone has been on your payroll for years. Someone is the person that is always going to do something Someday.)

Well, Someone never got back to us with the steps to the appeals process. In fact, Kristi made the same request for Someone to return her call on at least three other occasions. No call. Returning telephone calls is a basic business courtesy — much like submitting claims without using those ghastly, insidious staples or the timely payment of premiums.



5. Finally, Kristi was able to talk to Dawn to try to get some information. Dawn said that the claim for the insert had been denied in error and a check would be processed in the next 10 days. She went on to say that the reason the payment would be made was because we had been assigned to Medical Case Management. Well, this was news to us. We have experience with Medical Case Management because my employer's previous insurance carrier placed us on their MCM

continued on page 32

program. We received phone calls at least two or three times a week from the nurse that was assigned to us, and the results were actually very good. When my employer began coverage with your company, I spoke with a representative early in our relationship and asked if the Medical Case Management would continue. The representative told me that your company's strategy would be to "wait and see what happens, and I'll have Someone contact you if Medical Case Management becomes necessary."

Well, Sometime, Someone placed us on Medical Case Management, but as usual, Someone never contacted us. Kristi learned during her telephone conversation with Dawn that being on Medical Case Management entitled us to an extended number of therapy visits. I suspect that the reason this fact was not communicated to us was simple: "If the Whitlows know that (more visits) are available, they will probably go to the therapist more often." Well, let me tell you, you've got me there. Nothing gives me more pleasure than taking the time to bring Ashley to the therapist, and the ever-popular fitting for braces. What a thrill!

What you people don't seem to understand is that this therapy (and the seat insert, I might add) is necessary to maintain Ashley's circulation and help her remain upright, which will assist her in fighting respiratory problems and organ failure later on. This will result in lower medical bills in the future (and extend her quality of life and life span also). But, I realize this is not a concern of yours.

6. In March, Dawn called Kristi at home to explain that she had made a mistake. The information had been sent down to "the nurse" who ruled that this insert was not "medically necessary."

Kristi asked if she could speak to the nurse concerning the rationale, if any, behind her decision. Kristi was told that it would not be possible for her to speak to the nurse because, "If we let customers speak to the nurses, they would never have time to get their work done." This approach is too obtuse for words. I'll not labor this point any further.

Well, Kristi asked about the qualifications of this faceless, mute and nameless nurse (who is, no doubt, blood kin to Someone). Dawn told Kristi that "all of the nurses are equally qualified." This declaration is not exactly a source of comfort.

I'll tell you what: Go to your local hospital and visit the neonatal ICU, cancer and burn wards and find out for yourself how equally qualified the nurses are. I do not question their skills, but their level of expertise drops outside their areas of specialty.

At this point in the conversation, Dawn asked Kristi if she would like to talk to a supervisor. Kristi said that she would. The supervisor restated that the claim would be denied because the insert is not medically necessary. It was apparent that the buck would have to

be put on hold here.

Kristi asked why we had not been notified that we had been placed on Medical Case Management. The supervisor's response was, "All we can do here is apologize." This statement is probably closer to the truth than anything else we have heard from your company.

The basis for our appeal is this:

- The seat insert is medically necessary. The information you received from our adaptive equipment dealer (if you read it) indicated this fact.

- The seat insert is consistent with other equipment that you have paid for in the past (i.e. braces, IFO's, etc.). Try to read this letter flat on your back without the use of your arms and think again about what is medically necessary.

If you need more information processing this appeal, please have a *person with a name* contact me promptly. Please do not have Someone call me.

Even if this claim remains denied, I think you have a larger service issue that needs to be addressed. Successful companies all over the world are finding that their success depends on quality Customer Service. From all appearances, you have not jumped on the bandwagon. Basic business practices such as job knowledge, truth and follow-through seem to have fallen through the cracks.

If your company does not learn to conduct its business in a professional, efficient manner, you will not survive. You will find me shedding no tears. Take a look around, though. I'm sure Someone will be to blame. EP

Ryan J. Whitlow lives in Oklahoma City, Okla., with his wife, Kristi, and daughters Leslie, 9, and Ashley, 6. He is a training specialist for Scrivner, Inc., a wholesale grocery company.

Whitlow's insurance claim appeal letter was submitted to *Exceptional Parent* by Ashley's physical therapist, Mary Deaton-Pickett. She wrote "(The Whitlows) had been in a several month battle with their insurance company regarding payment for an adaptive seat insert for Ashley's wheelchair. I was so impressed with this letter (because it) expresses Mr. Whitlow's anger and frustration, but also shows his determination not to give up as well as the *most* important thing — a sense of humor, (which is) imperative for our families to survive. I hope you see the universal nature of (a situation) that *many* families have to endure."



Photo by Olan Mills.



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Baby Girl



ur story starts out like the Great American Dream. Man falls in love with Woman. Woman falls in love with Man. They get married and buy a home. A short time later, their firstborn — a son — comes along, whole and happy. Life is tough but it is good. A little while later, a second child is on the way. This pregnancy is different, very difficult.

But no need for alarm. Complications with the pregnancy occur and the baby is born 15 days early. Still no cause for alarm. The little girl weighs in at six pounds, three ounces and measures 18 1/2 inches. Apgars are fine. On the third day, the family goes home believing again that all is fine in their world. And life goes on.

For the next six weeks they believe that all is well until the pediatrician becomes concerned with the baby girl's lack of development. Still there is no great panic. The doctor says to give the baby girl some time to catch up, since she was a bit premature. So again there is no panic, just caution. By the eighth week, concerns are very real and the doctor would feel better if mom and dad took baby to see a neurologist in the Big City. He would know what to do.

So to the Big City they go. They see the neurologist. He talks very openly and decides to order many tests — some today, some in a couple of weeks. But he does suspect a problem. The test results are finally known. The baby girl is not perfect. Her brain has stopped growing. He calls

it a big word but the parents don't hear anything but the sound of their own hearts falling to the bottom of their chests. How? Why? Those words are all that can be

heard over the tears. The advice from the neurologist is to get enrolled in an early stimulation program and to come back for check-ups. So the mother follows the neurologist's advice and calls the nearest rehabilitation hospital.

The baby girl was born in late March. Time passes while paper work and phone calls fill the family's life and now it is August. They go to their first therapy visit. The family could never have guessed the amount of time and effort it takes to care for their baby girl. But love has a way of making the job a little bit easier. And life goes on.

It's now December of the first year and baby girl is sick with a bad cold. Christmas is at the end of the week and the weather is cold but they have to keep their appointment with the

neurologist. He comes into the room, does his evaluation, hands the baby girl back to her mother and makes his announcement. "I see no significant changes in her



by Geraldine G. Miller

development and I think considering your age ... you have one healthy child and may have more. Considering the financial costs involved, you should put the baby girl's name on a waiting list for a residential home."

The statement is cold. The mother can tell it has been said many times before by this man. It is almost Christmas — the time of hope and miracles. How could he tell her this now? The baby is sick; of course she won't do well with the tests. All of this goes through the mother's mind in a split second. But instead of falling apart and walking away, the mother strikes back.

"How can you tell me this? She's not a puppy dog I can't housebreak. I won't just drop her by the wayside because it would be easier. My husband and I chose to have her as we chose to have our son. That meant whatever God gave us — good or bad."

As the mother says this, she has many tears falling down her face. She hurts. And the hurt from those words — and the words themselves — will for all time be in the mother's mind. Never will she forget the anger of those words. This child was her daughter, her flesh and blood. She would be the one to take care of the baby girl. For no institution, no matter how wonderful, can ever take the place of a mother's love.

The story does not end here. The baby girl is now two and a half years old and is just what the neurologist said she would be. But she makes progress with her therapy. She has a very special bond with her older brother. The pediatrician from the beginning of the story takes very good care of her as well as the family. He has been there for the family in times of doubt and in times of joy. He watches her change ever so slightly, but the changes are there. He has given his home phone number to the mother and been there in the wee hours of the morning when the fears and the tears of the night are the worst.

In the beginning, he held the family's hand as they made the decision to keep the baby girl at home. And after the baby girl's first birthday, he confided to the mother that only through her love was the baby girl able to live. He had had dark thoughts that this day would never come. He was glad to be wrong. He has often said

prayers for the baby girl. And the mother and father know that without his support in the beginning, this story would not be told. He gave them the ability to move on with their lives and to grow with the baby girl in ways their son could never have given them.

Recently the baby girl reached a new milestone. No, she's not sitting or rolling. It's as simple as a laugh. It took 31 months but it never would have been witnessed by mother and father if Dr. Depressing had had his way.

So I say to all the Dr. Depressings of this world — come forward into the 20th century. If you cannot see the small miracles in life, how will you ever be able to appreciate the large ones?

And to the pediatrician — I hope someday all doctors can look at the example you have set and make it a personal goal. Your true reward will not be the little gifts the baby girl gives you at Christmas but in the place we both know is waiting for us all someday.

I tell this story today without names because the story is what is important, not the people. And there are many other

people in this story we have met — most of whom have helped us along the way. Some do fall in with Dr. Depressing, but mostly, people have supported us. And, of course, the story continues.

Life is still difficult, but it is good! EP



Rebekka and her big brother Justin display some sibling bonding.



Geraldine G. Miller is a full-time mother and wife who calls herself her "children's best advocate." She lives in Sewickley, Penn., with her husband, Kirk, and children, Justin, 5, and Rebekka, 3. Rebekka has multiple disabilities, including microcephaly, cortical blindness, hearing loss in one ear, facial asymmetry and spastic quadriplegia. Miller says that "no matter what the developmental scale says about Rebekka's abilities or disabilities, she is a person all unto herself, with a personality bursting out with love."

FUNDING ADVOCATE

An early task in the funding procurement process is to identify the funding advocate. The fact that funding for a communication device is being sought suggests that the person who relies on AAC is unable to speak for himself. Therefore, until the time that the person who relies on AAC has an effective system and the skills to use it, an advocate must represent the interests of that person in many matters. *Funding will not happen without a dedicated advocate.*

THE PERSON WHO RELIES ON AAC

Qualify the person who relies on AAC. What is the main purpose for the device? Is it considered a medical necessity, a tool for further education, or a means of gainful employment? To approach a school with the argument of medical necessity or to approach Medicaid with the argument that it will interface with a computer will not serve you well.

Funding Devices and Services in Augmentative and Alternative Communication

Communication is the essence of human life. Article II, Section 1 USSAAC Bylaws

Personal achievement is closely tied to the ability to communicate. Because of the significant effect on a person's life, *this is no place* for compromises based on cost or convenience. People who rely on augmentative and alternative communication (AAC) are served best only when provided with the AAC device and services that offer the *most effective* communication possible.

Fortunately, experience has shown that no such compromises are necessary. When a person who relies on AAC has a good advocate, the funding can always be found for the most appropriate devices and services available.

Funding for the Most Appropriate is Always Available!!

FUNDING SOURCES

There are many sources of funding for AAC devices and services and it is important to approach them in the proper order. Either Schools, Insurance, Medicaid, or the Vocational Rehabilitation agency should be tried first and all avenues within that source should be exhausted before trying one of the lower level options. Each source has its own procedures and policies. Before submitting an application for funding, familiarize yourself with them and do research to determine what has worked for others.

INSURANCE/MEDICAID

These are the sources to approach with a claim of medical necessity. A number of progressive insurance companies and state Medicaid programs already recognize communication aids as a medical necessity and fund them. There are still those, however, who have not yet responded to the opportunities available to people with disabilities as a result of new technologies. In some cases, it is because they have not been exposed to them. Use terms such as "speech prosthesis" which may position the device more favorably. Bringing the person who relies on AAC to the agency can be an effective means of educating them. Remember that denial is not an end point unless you let it be one. If you are denied, make it clear that you will appeal and eventually sue - and then do it! This has been done with success, ultimately changing the system in those areas and paving the way for future people who rely on AAC.

SCHOOLS

Without a means of communication, it is difficult to participate meaningfully in the education process. For that reason, schools have been known to purchase devices, especially when it has been written into the IEP. Remember, however, that the device then belongs to the school, not the person who relies on AAC. This may require the student to leave the device at school after school hours, during the summer, and permanently, after graduation or when moving out of the school system.

VOCATIONAL REHABILITATION PROGRAMS

Since employment is becoming a realistic goal for many people with disabilities, vocational rehabilitation programs will often fund augmentative communication devices if the main obstacle to employment is communication. Because these are also state run programs, the eligibility requirements vary from state to state. Contact your local vocational rehabilitation office which should be listed in the white pages of the phone book under your state's name.

OTHER ENTITLEMENT PROGRAMS

There are many federal, state, and local programs that now provide AAC devices and services. Be sure to check to see if you qualify for any. For example, the Veterans Administration has been a forerunner in the field of assistive technology. Others include workers compensation, children's rehab services, MRDD, and independent living.

PRIVATE CORPORATIONS / FOUNDATIONS / TRUST FUNDS

Many companies make charitable contributions directly or have associated foundations. Also, trust funds are established often by individuals. One source of information is the *Handicapped Funding Directory* which lists grants and foundations. It is available from Research Grant Guides, P.O. Box 1214, Loxahatchee, FL 33470.

SERVICE CLUBS / CIVIC GROUPS

Local civic organizations such as Kiwanis, Rotary, and Lions Clubs have often contributed to the purchase of equipment. Since funds are usually limited, it is best to use them sparingly and to suggest a "matching funds" arrangement with another funding source.

FUND-RAISERS

Families often have affiliations with groups which may assist in a fund-raising activity. Churches, co-workers and other organizations (such as labor unions) have successfully raised funds by conducting raffles, bake sales, car washes, dinners, and other creative activities.

WISHMAKERS"

There are a handful of individuals and organizations which grant wishes to people with specific needs. Two such organizations are listed below.

- The Sunshine Foundation grants wishes to children with chronic disabilities. An application must be completed and there is a maximum amount they will fund. Families should contact the Sunshine Foundation National Headquarters, 4010 Levick St., Philadelphia, PA 19135.
- The Make-A-Wish Foundation of America grants wishes to children under the age of twelve with life threatening illnesses. They are located in Phoenix, AZ. (602) 279-9474.

PUBLIC APPEALS

If other sources of funding have been exhausted, a public appeal is an option. This form of funding procurement is not suggested as a regular avenue because people tend to become jaded if exposed to too many. Also, the family is placed directly in the public eye which may be uncomfortable. It has proved to be a successful tactic in a number of cases, however.



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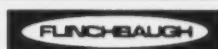
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Accessibility Offices



The following is a directory of government offices that will give advice and guidance to people with disabilities on accessible services, facilities, attractions and destinations in each state.

ALABAMA

Dept. of Tourism
401 Adams Ave.
Montgomery, AL 36103
(205) 242-4169

ALASKA

Division of Tourism
P.O. Box 110801
Juneau, AK 99811
(907) 465-2010

ARIZONA

Office of Tourism
1100 West Washington
Phoenix, AZ 85007
(602) 542-8687

ARKANSAS

Dept. of Parks and Tourism
One Capital Mall
Little Rock, AR 72201
(800) NATURAL

CALIFORNIA

Office of Tourism
801 K Street, Suite 1600
Sacramento, CA 95814
(916) 322-1397

COLORADO

Dept. of Tourism
1625 Broadway
Suite 1700
Denver, CO 80202
(303) 592-5410

CONNECTICUT

Development and Tourism
865 Brook St.
Rocky Hill, CT 06067
(203) 258-4355

DELAWARE

Tourism Office
99 Kings Hwy.
P.O. Box 1401
Dover, DE 19903
(800) 441-8846

DISTRICT OF COLUMBIA

Convention and Visitor Ctr.
1212 New York Ave. NW
Washington, DC 20005
(202) 789-7000

FLORIDA

Division of Tourism
107 W. Gaines St.
Suite 501D
Tallahassee, FL 32399
(904) 487-1462

GEORGIA

Tourist Division
285 Peachtree Ctr. Ave. SW
Suite 1000
Atlanta, GA 30303-1232
(404) 656-3590

HAWAII

Visitor's Bureau
2270 Kalakaua Ave.
Suite 801
Honolulu, HI 96815
(808) 923-1811

IDAHO

Idaho Travel Council
700 W. State St.
Boise, ID 83720-2700
(800) 635-7820
(208) 334-2470

ILLINOIS

For a list of regional information telephone numbers:
(312) 793-2094

INDIANA

Dept. of Commerce
Tourism Division
One North Capital
Suite 700
Indianapolis, IN 46204
(317) 232-8860

IOWA

Dept. of Economic Development, Tourism Div.
200 E. Grand Ave.
Des Moines, IA 50309
(800) 345-4692
(515) 242-4705

KANSAS

Division of Tourism
400 SW Eighth Street
Suite 500
Topeka, KS 66603
(913) 296-2009

KENTUCKY

Dept. of Travel Development
Capitol Plaza Tower
500 Mero St.
Frankfort, KY 40601
(800) 225-8747
(502) 564-4930

LOUISIANA

State Office of Tourism
(800) 33-GUMBO

MAINE

Publicity Bureau
P.O. Box 2300
Hallowell, ME 04347
(207) 582-9300

MARYLAND

Dept. of Tourism
217 E. Red Wood St.
Ninth Floor
Baltimore, MD 21202
(800) 543-1036

MASSACHUSETTS

Office of Travel and Tourism
100 Cambridge St.
13th Floor
Boston, MA 02202
(617) 727-3201

MICHIGAN

Travel Bureau
(517) 373-1700

MINNESOTA

Office of Tourism
121 East Seventh Place
Metro Square
St. Paul, MN 55101
(800) 657-3700

MISSISSIPPI

Metro Jackson Convention and Visitor's Bureau
P.O. Box 1450
Jackson, MS 39215-1450
(601) 960-1891

MISSOURI

Division of Tourism
P.O. Box 1055
Jefferson City, MO 65102
(314) 751-4133

MONTANA

Travel Montana
1424 Ninth Avenue
Helena, MT 59620
For specific city:
(800) 548-3390

NEBRASKA

Nebraska Tourism
P.O. Box 94666
Lincoln, NE 68509
(402) 471-3796

NEVADA

Commission of Tourism
5151 South Carson
Carson City, NV 89701
(800) 237-0774

NEW HAMPSHIRE

Office of Travel and Tourism
P.O. Box 856
Concord, NH 03302-0856
(603) 271-2343

NEW JERSEY

Office of Travel and Tourism
20 W. State St.
Trenton, NJ 08625
(800) JERSEY
(609) 292-2470

NEW MEXICO

Dept. of Tourism
Lamy Building
491 Old Sante Fe Trail
Sante Fe, NM 87501
(505) 827-0291

NEW YORK

Division of Tourism
One Commerce Plaza
Albany, NY 12245
(800) CALL-NYS
(518) 474-4116

NORTH CAROLINA

Department of Tourism
430 N. Salisbury St.
Raleigh, NC 27611
(800) 847-4862

NORTH DAKOTA

Tourism Division
604 East Boulevard
Bismarck, ND 58505
(701) 224-2525

OHIO

Dept. of Travel and Tourism
77 S. High St., 29th Floor
Columbus, OH 43266
(800) BUCKEYE
(614) 466-8844

OKLAHOMA

Tourism and Recreation
241 North Lincoln
500 Will Rogers Building
Oklahoma City, OK 73105
(405) 521-2406

OREGON

State Office of Tourism
(503) 378-3451

PENNSYLVANIA

Travel Development
453 Forum Building
Harrisburg, PA 17120
(717) 787-5453

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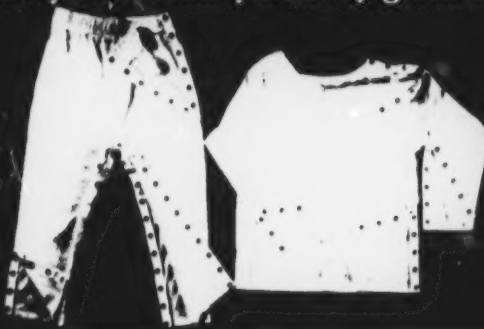


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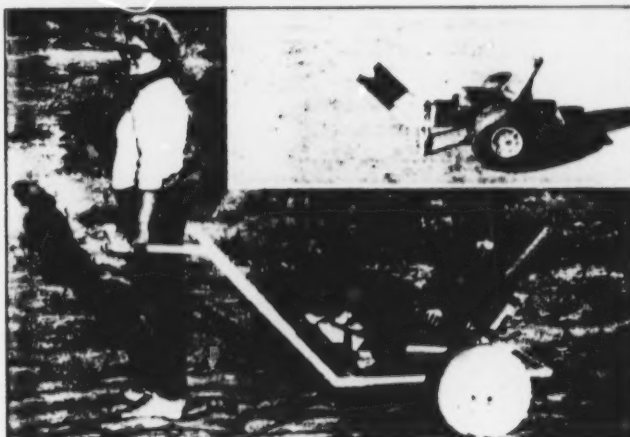
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Old San Juan Station
San Juan, PR 00905
(809) 721-1712

RHODE ISLAND

Rhode Island
Dept. of Economic
Development
7 Jackson Walkway
Providence, RI 02903
(401) 277-2601

SOUTH CAROLINA

Department of Parks,
Recreation and Tourism
Edgar Brown Building
1205 Pendleton St.
Suite 106
Columbia, SC 29201
(803) 734-0122

SOUTH DAKOTA

South Dakota
Tourism Office
Capital Lake Plaza
711 East Wells
Pierre, SD 57501-3369
(800) 843-1930

TENNESSEE

Tennessee Tourist
Development
P.O. Box 23170
Nashville, TN 37202-3170
(615) 741-2158

TEXAS

Travel/Information Division
125 East 11th Street
Austin, TX 78701-2483
(512) 463-8586

UTAH

Travel Council
Council Hall, Capitol Hill
Salt Lake City, UT 84114
(801) 538-1030

VERMONT

Division of Vocational
Rehabilitation
103 S. Main St.
Waterbury, VT 05671-
2303
(802) 241-2186

VIRGINIA

Tourism Development
Group
1021 E. Cary St.
Richmond, VA 23219
(804) 786-4484

WASHINGTON

Dept. of Commerce and
Economic Development
Tourism and Travel
Division
P.O. Box 42513
Olympia, WA 98504-2513
(800) 544-1800
(206) 586-2102 or 2088
(Ask for resource guide 71)

WEST VIRGINIA

Division of Tourism
Parks and Recreation
State Capitol Complex
Building 6, Room B564
Charleston, WV 25305
(800) 225-5982
(304) 348-2764

WISCONSIN

Wisconsin Travel
Information Center
P.O. Box 7606
Madison, WI 53707-7606
(608) 266-2161

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Division of Tourism
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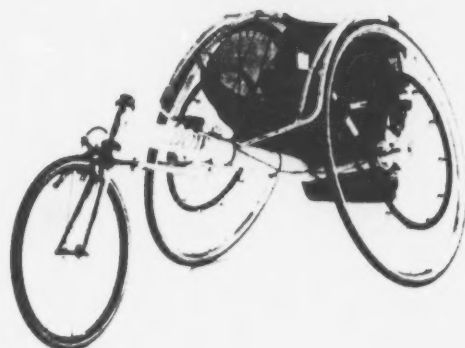
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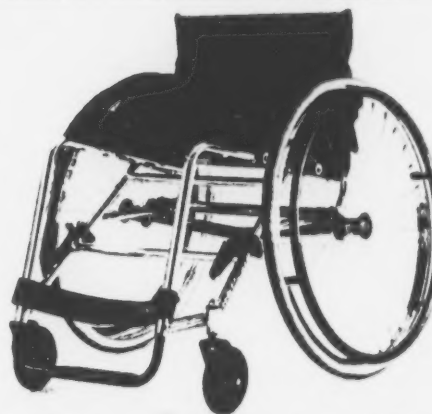
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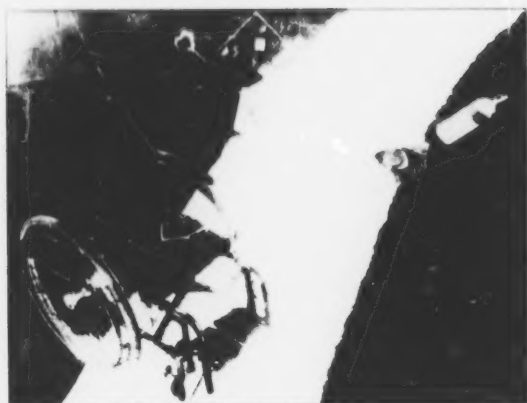
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Back Height	12" - 20"
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Total Weight	17-20 lbs.

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QUICKIE DESIGNS



ZIPPIE 2

What You Should Know...

At the heart of the Zippie 2 is a completely new frame design, with a folding back and crossbrace. So the Zippie folds flat for easy transportability to all the places kids need to go. The Zippie 2 also has an innovative new growth system, with replaceable folding crossbrace to increase width, and an adjustable seat back that grows in depth.

Want to Know More?
(800) 456-8168

PRODUCT SPECIFICATIONS

Seat Depth	10' - 16"
Seat Width	12' - 16"
Back Height	11"/12", 13"/14", 15"/16"
Weight Capacity	150 lbs.
Total Weight	31 lbs.

Suggested Retail Price
\$1,825



QUICKIE DESIGNS INC.
2842 Business Park Avenue
Fresno, CA 93727
(209) 292-2171



ZIPPIE TS

What You Should Know...

Zippie TS features a fully adjustable frame, with replaceable cross members for "growability." Its angle-adjustable back folds down for storage and easy transport. And Zippie TS is available with a full range of easily tailored options for kids, including tilt-in-space and swing-away footrests. Available in 13 different colors, it has all the stylish good looks you expect from a Quickie.

Want to Know More?
(800) 456-8168

PRODUCT SPECIFICATIONS

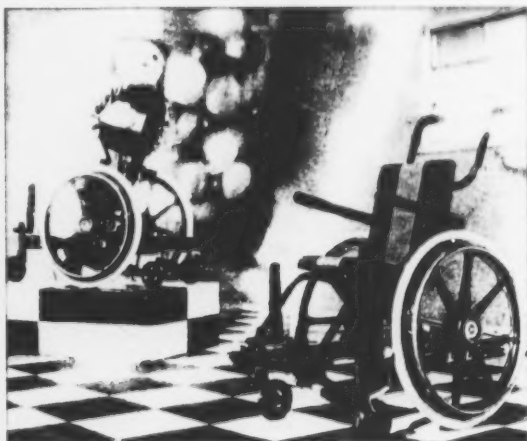
Seat Depth	10' - 16"
Seat Width	10' - 16"
Back Height	11"/12", 13"/14", 15"/16"
Weight Capacity	150 lbs.
Total Weight	32 1/2 lbs.

Suggested Retail Price
\$2,200



QUICKIE DESIGNS INC.
2842 Business Park Avenue
Fresno, CA 93727
(209) 292-2171

QUICKIE DESIGNS



ZIPPIE 3

What You Should Know...

Zippie 3 is a kids' tilt-in-space chair that's also a mobile stander. With a few simple adjustments, the Zippie 3 converts from a wheelchair to a stander in minutes. As a wheelchair, the Zippie 3 comes standard with tilt-in-space and a low center of gravity for maximum support and stability. As a stander, it enables children to stand up and propel themselves.

Want to Know More? (800) 456-8168

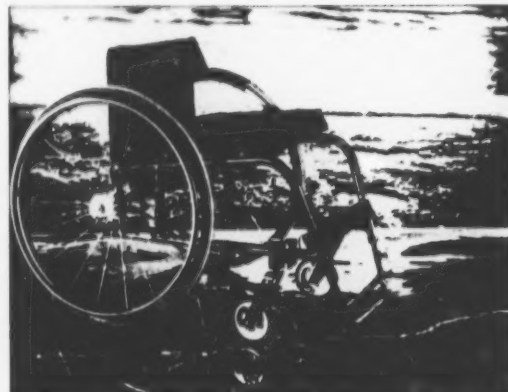
PRODUCT SPECIFICATIONS

Seat Depth	10", 12", 14", 16"
Seat Width	10", 12", 14", 16"
Back Height	14", 16", 18"
Frame Width	10", 12", 14", 16"
Weight Capacity	100 lbs.
Total Weight	Wheelchair: 38 1/2 lbs. Stander: 30 lbs.

Suggested Retail Price
\$3,495



QUICKIE DESIGNS, INC.
2842 Business Park Avenue
Fresno, CA 93727
(209) 292-2171



QUICKIE GP

What You Should Know...

With its rigid, lightweight frame, Quickie GP rolls surely and effortlessly, without flex or sway. It's totally adjustable, so you can fine tune such features as axle position, center of gravity and chair angle to meet the demands of your life. And you can customize your Quickie GP with the widest range of optional footrests, casters, custom sizes and front frames.

Want to Know More? (800) 456-8168

PRODUCT SPECIFICATIONS

Seat Depth	14" - 18"
Seat Width	11 1/2" - 19 1/2"
Back Height: Fixed	8" - 16"
Back Height: Folding	11" - 14"; 12" - 16"
	14" - 18"; 16" - 20"
Frame Width	12" - 20"
Weight Capacity	250 lbs.
Total Weight	19 3/4 lbs.

Suggested Retail Price
\$1,675



QUICKIE DESIGNS, INC.
2842 Business Park Avenue
Fresno, CA 93727
(209) 292-2171

QUICKIE DESIGNS



ZIPPIE P500

What You Should Know...

The Zippie P500 is a powered chair with an efficient Direct Drive Motor System and controller for child-tailored performance. It comes with tilt-in-space, standard, and grows with your child like our original Zippie does. And with its downsized power base, smaller seating unit and 13 color options, the Zippie P500 is a kids' chair from top to bottom.

Want to Know More?
(800) 456-8168

PRODUCT SPECIFICATIONS

Seat Depth	10" - 15"
Seat Width	12" - 16"
Back Height	11"/12", 13"/14", 15" - 16"
Weight Capacity	150 lbs.
Total Weight	75 lbs. without batteries

Suggested Retail Price
\$5,398



QUICKIE DESIGNS, INC.
2842 Business Park Avenue
Fresno, CA 93727
(209) 292-2171

PRIME ENGINEERING



KIDSTAND

What You Should Know...

This stand will accommodate children 3' to 4' 6", with multiple adjustment for custom fitting. Hydraulics slowly lift child to standing position by simply placing sling under child and pumping handle.

Also available:

Kidstand P. S. - Prone stander w/ mobility package and Kidstand U. P. - Upright Stander.

Want to Know More?
(800) 82-STAND

PRODUCT SPECIFICATIONS

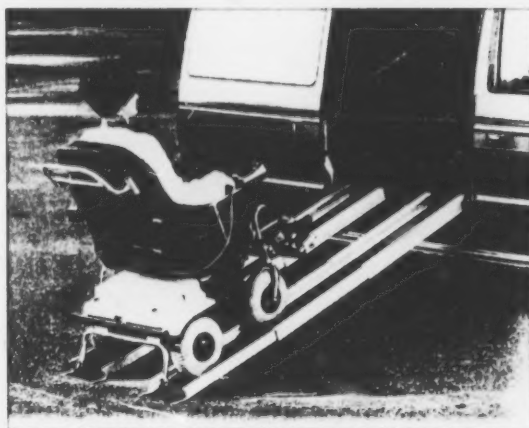
Base Size	32" x 30"
Table Top	18" x 26 1/4"
Height Range	35 1/2" to 43 1/2"
Weight Capacity	150 lbs.
Total Weight	68 lbs.

Suggested Retail Price
\$1,695



PRIME ENGINEERING
4838 W. Jacquelyn #105
Fresno, CA 93722
(209) 76-0991

HOMECARE PRODUCTS, INC.



EZ-ACCESS VANRAMP 7' & 10'

What You Should Know...

Introducing the EZ-ACCESS™ VANRAMP, the frontrunner in telescopic ramps for manual and electric wheelchairs. The EZ-ACCESS™ VANRAMP bridges gaps over steps and curbs, but also makes vans and mini-vans more accessible. Sturdy construction promotes years of convenient use. Durable non-skid tread enables optimum traction even when wet.

Want to Know More?
(800) 451-1903

PRODUCT SPECIFICATIONS

Anodized Aluminum Construction	
Non-Skid Driving Surface	
Telescopic Design	
Safety Bolt Attachment	
Inside Width	6 1/2"
Collapsed Length of 7'	3'
Collapsed Length of 10'	49"
Weight Capacity	600 lbs.

Suggested Retail Price
7' - \$320.95, 10' - \$399.95



HOMECARE PRODUCTS INC.
15824 SE 296 Street
Kent, WA 98042
(800) 451-1903



EZ-ACCESS PORTABLE 5'

What You Should Know...

The lightweight EZ-ACCESS ramp bridges the gaps over steps and curbs. EZ-ACCESS' two ramps extend to over five feet in length. Users simply align their wheels in the U-shaped track and roll-up, or down, steps. The durable, non-skid tread enables optimum traction even when wet. The two ramps are stored in a pouch that hangs on the back of the wheelchair.

Want to Know More?
(800) 451-1903

PRODUCT SPECIFICATIONS

Anodized Aluminum Construction	
Non-Skid Driving Surface	
Carrying Bag	
Telescopic Design	
5' Extended, 27 1/2" Collapsed	
Inside Width	4"
7 Lbs Per Side-Rail	
Weight Capacity	350 lbs.

Suggested Retail Price
\$179.95



HOMECARE PRODUCTS INC.
15824 SE 296 Street
Kent, WA 98042
(800) 451-1903

HOMECARE PRODUCTS, INC.



EZ-ACCESS SCOOTER 8'

What You Should Know...

The EZ-ACCESS R3000 makes vans and mini-vans accessible to three-wheel scooters and all conventional wheelchairs. The EZ-ACCESS R3000 features side rails and center panels that lock securely into place to provide a solid driving surface. The telescoping and lightweight design of the EZ-ACCESS R3000 allows for convenient storage and use wherever you need to go.

Want to Know More?
(800) 451-1903

PRODUCT SPECIFICATIONS

Anodized Aluminum Construction	
Non-Skid Driving Surface	
Telescopic Design	
Safety Bolt Attachment	
Collapsed Length of Tracks	39"
Inside Width	28 1/2"
Outside Width	31"
Weight Capacity	750 lbs

Suggested Retail Price
\$499.95



HOMECARE PRODUCTS INC.
15824 SE 296 Street
Kent, WA 98042
(800) 451-1903



EZ-ACCESS ROLL-UP 3' & 5'

What You Should Know...

Introducing the EZ-ACCESS ROLL-UP™, the newly designed portable ramp for scooters and wheelchairs. Set up of the EZ-ACCESS ROLLUP™ is as simple as rolling out the non-skid track and latching on the two side rails. EZ-ACCESS ROLL-UP™ features a durable non-skid driving surface, and nylon storage bag.

Want to Know More?
(800) 451-1903

PRODUCT SPECIFICATIONS

Anodized Aluminum Construction	
Non-Skid Surface	
Nylon Storage Bag With Handle	
Inside Width	30"
Outside Width	30 1/2"
Weight Capacity	600 Lbs.
Total Weight of 3'	17 Lbs.
Total Weight of 5'	28 Lbs.

Suggested Retail Price
3' - \$179.95, 5' - \$324.95



HOMECARE PRODUCTS INC.
15824 SE 296 Street
Kent, WA 98042
(800) 451-1903

CONVAID



THE CRUISER

What You Should Know...

The Cruiser buggies are specially designed to provide firm positioning and maximum support for children of all ages with special needs. Durable yet lightweight, the Convaid Cruiser is made to travel and folds easily into the trunk or backseat. Fully adjustable, it is available in three age-specific models to keep up with a child's ever-changing needs. Capable of over 20 different positioning features, the Cruiser can be tailored to each child with a full range of positioning adaptations.

Want to Know More?
(800) 552-1020

Suggested Retail Price
\$487 & up

Why You Should Buy...

Expandability/Adjustability

Three sizes for infants through teens. Standard: adjustable seat depth, back angle and foot support. Full range of positioning options and accessories. Crash-tested bus tiedown model also available.

Adaptability for special seating needs

This is a comprehensive positioning buggy. Modified frame also available to carry Britax or Columbia Car Seat.

Durability/Portability

- All steel frame with wheelchair-quality wheels and casters. Fabric is non-stretch, breathable, fire-retardant, waterproof and fungus resistant.
- Lightweight, compact and umbrella-folding for easy travel or storage. Weight of Model 4M shown: 17 pounds (without accessories).

Instructional Manual

All Cruiser buggies come with a detailed four-page instruction booklet covering adjustments, accessories and basic maintenance.

Serviceability

Wheels, casters, fabrics, accessories, and most parts are available for replacement through dealer or factory.

Unique Features

•Folds compactly with all adaptations in place •Patented folding safety mechanism eliminates the hazard of accidental folding and orthopedically damaging "buggy slump" •Machine washable fabric seat & accessories are easily removed for cleaning.

Colors

Royal blue, burgundy and calypso.

PRODUCT SPECIFICATIONS

Seat to Footrest	6" - 14"
Seat Measurements	13"W/12 1/2" - 14 1/2" D
Back Angle	25 - 30 - 35 degrees
Seat Back Height	22"
Seat Back Height w/Extension	27"
Shoulder Strap Height	14" - 20"
Weight Capacity	125 lbs.
Weight (without accessories)	17 lbs.

 **Convaid**
PRODUCTS INC

CONVAID PRODUCTS, INC.

P.O. Box 2458

Palos Verdes, CA 90274

(800) 552-1020 or (310) 539-6814

CONVAID



COMPAX CHAIR

What You Should Know...

The Compax from Convaid is an ultralight, folding, upright chair with the sturdy support and carrying capability of a heavy wheelchair, without the added bulk. The steel frame of the Compax combines the strength of steel with the lightness of aluminum, which adds up to superior construction and comfort. Designed to travel, the Compax chair is so compact it folds to the size of a small golf bag thanks to its innovative patented folding mechanism.

Want to Know More?
(800) 552-1020

Suggested Retail Price
\$789 & up

Why You Should Buy...

Expandability/Adjustability

Adjustable, detachable swing-away footplates. Detachable flip-up armrests. Optional 12" rear wheels, self-propelled model and amputee version.

Adaptability for Special Seating Needs

Suitable for seating system insert.

Durability/Portability

- Steel reinforced aluminum frame designed to carry 250 pounds.
- Basic lightweight Compax 17CL model (shown) weighs only 19 pounds and folds to the size of a small golf bag for easy portability.

Instruction Manual

Comes with a two-page instruction booklet complete with folding/unfolding instructions and maintenance tips.

Serviceability, Warranty

Five-year warranty on frame, one-year on fabrics. Wheels, casters and most parts are easily replaced by dealer or factory.

Unique Features

- The ultralight weight and compact fold make the Compax an ideal indoor-outdoor traveling chair.
- Adjustable toggle brake can be readjusted in seconds for tire wear.

Colors

Royal blue, burgundy and calypso.

PRODUCT SPECIFICATIONS

Overall Height (open)	36 1/2"
Overall Dimensions (folded) with footplates	11"x11" x 45 1/2"
Seat to Footrest	16" x 20 1/2"
Seat Measurements	17 1/2"W/16"D
Seat Back Height	17"
Weight Capacity	250 lbs.
Weight (without front rigging)	19 lbs.

Convaid
PRODUCTS INC

CONVAID PRODUCTS, INC.
P.O. Box 2458
Palos Verdes, CA 90274
(800) 552-1020 or (310) 539-6814

KID-KART *cares about kids*



What You Should Know...

The Kid-E-Plus Package 1 and Package 2 prove that good looks, versatility and proper positioning work wonderfully together. The Kid-E-Plus is a lightweight, primary use chair that is versatile enough to allow easy maneuverability in the home and school environment, yet sturdy enough to enable outdoor mobility and features a number of accessories for convenience and comfort. The adjustable handle bar makes it comfortable for the parent. The Kid-E-Plus Modular Positioning System will accommodate special children within the full spectrum of severity with varying degrees of involvement and is adjustable, allowing for many years of growth.

Want to Know More?
(800) 388-5278

THE KID-E-PLUS™

Three Models to Choose From.

Why You Should Buy...

Convenient

Lightweight,
compact,
easy to fold.

Growth

The Kid-E-Plus Modular Positioning System grows from infant to approximately 7 years old. The larger Kid-E-Plus 'X' grows to approximately age 11.

Unique Features

Easy Single-Pull Tilt-In-Space adjustment. Recline Option. Contoured Seat Cushion allows growth in width and depth. Bus/Van Tie Down Model Option.

Accessories

Including: Swing-away lateral supports, therapeutic tray, head supports, hip guides, elbow blocks. Custom seat back and bottom cushions. Made-to-order Custom options.

Versatility

High performance in the home or school as well as in the outdoors. Send your child to school in the Kid-E-Plus Bus/Van Tie Down Model.

Comfort & Proper Positioning

You choose between the 'Package 1 Planar Seating System' and the 'Package 2' with Contoured Seat Cushion and the Modular Positioning System.

Durability, Warranty

Two year warranty excepting tires and tubes. Wheels, fabrics, parts and repair are available through the factory. Comes with instructions and operation manual.

Product Specifications

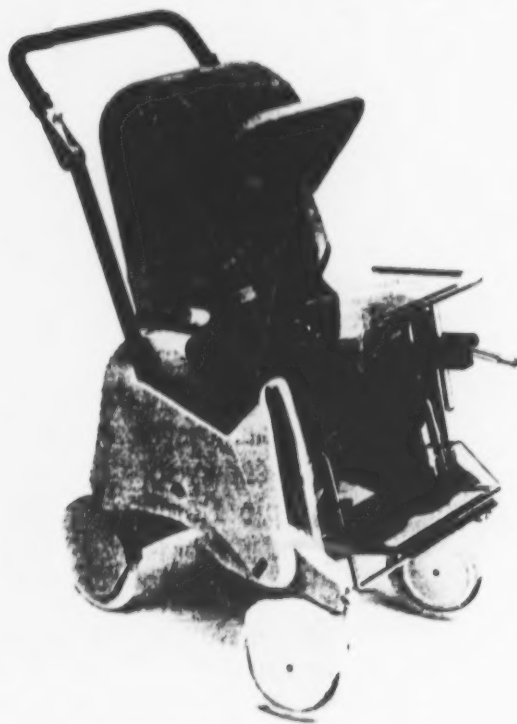
Growth	Kid-E-Plus - to age 7 / 'X' model - to age 11
Tilt-In Space	Single pull adjustment, tilt to 30°
Seat to Footrest	Plus, 6" - 12" / 'X', 10" - 15"
Seat Width	Plus, 7" - 13" / 'X', 7" - 15"
Seat Depth Adjustability	Plus, 6" - 12" / 'X', 9" - 15"
Hip Angle	3 position recline option
Weight	24-29 lbs.

MADE-TO-ORDER CUSTOM OPTIONS

kid-kart™

KID-KART *cares about Kids*
126 Rosebud, Suite #1
Belgrade, MT 59714
(800) 388-5278

SHUTTLE SE



SHUTTLE SE

What You Should Know...

The SHUTTLE SE is a premium special needs stroller and car seat that provides all the necessary support, safety and comfort its passenger will need. Designed specifically for young children with special abilities, the innovative two-in-one SHUTTLE SE eliminates the struggle of transferring from car seat to stroller. As a lightweight stroller, it can be converted instantly to a car seat and then back again without the child ever leaving his or her seat. A precision performer, the SHUTTLE SE has all the features of a premium stroller plus an activity tray and adaptations that provide support and stability for that special passenger.

Want to Know More?
(617) 826-7447

Suggested Retail Price
See Your Local Dealer

Why You Should Buy...

Expandability

Accommodates newborn infants through toddlers. As a car seat, it has been crash-tested to 40 lbs. and meets FMVSS #213. It can be positioned rear facing for infants or forward for toddlers. As a stroller, it can carry up to 60 lbs.

Adaptability

Add-on Stabilizing supports for feet, legs, trunk and head. Five-point harness for support and safety. A removable activity tray for play, feeding and support.

Serviceability

All parts are readily available and most are serviced with an ordinary Phillips head screw driver. The seat cover is easily removable and is machine washable.

Adjustability

Seat back, seat angle, seat depth, and footrest are all fully adjustable. Stroller handle adjusts from 35" to 41" for parents of all heights. Handle reverses so parents can watch their child while out for a walk.

Portability

Stroller wheels fold into the seat body to become a compact 18" x 27" car seat weighing just 23 pounds.

Warranty

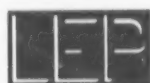
Two year limited warranty on parts and labor for the retractable wheel assembly; one year for all other parts.

Colors

Teal blue and grey.

PRODUCT SPECIFICATIONS

Seat Depth	8" - 12"
Seat Width	11"
Back Height	21"
Shoulder Strap Height	8" - 11" - 14"
Leg Drop	5" to 10.5"
Car Seat Capacity	40 lbs.
Stroller Capacity	60 lbs.



LIFE ENHANCEMENT PRODUCTS, LTD
400 Corporate Park / 300 Oak St.
Pembroke, MA 02359
(617) 826-7447 FAX (617) 826-5323

R. J. COOPER & ASSOC.



What You Should Know...

Finally, an affordable quality mobility training/experience for your child without the high cost of a custom power chair! The CooperCar is a modification to a commercially available "kid-car". Our adaptation allows a child to drive their own battery operated vehicle...using any ability whatsoever. If they can blink an eye, wiggle a finger, move their head, ANYTHING, they can drive the CooperCar. You can use any of the hundreds of switches made as the child's input. We also include a special joystick, either for the child's use, or yours as supervisor.

Available as a simple Conversion Kit, or assembled (Kit installed in vehicle).

Want to Know More?

Call us at (714) 240-1912 for Conversion Kit info
Call (800) TEC-TOYS for assembled CooperCar info.

COOPERCAR

Suggested Retail Price

\$595 kit only \$750 w/vehicle

Why You Should Buy...

Accept only the original CooperCar...
Ask for it by name!

There simply is no other CooperCar. BEWARE! You may see ads with products that look like ours, but they are simply imitations.

- We set the standards.
- We've fine-tuned our invention with hundreds of children.
- We've put in the 9 years with "your" children.
- We're the ones with the reputation of caring.
- We've been making hi-tech software for 9 years.

WE'RE KEEPING COSTS LOW!

Use your own adaptive seat. If you have a switch mounting like Magic Arm (Toys for Special Children)? Use it! Whatever you need to complete the package, we'll help you find it. We're on your side!

SAFETY & INDEPENDENCE

A "child-enable" switch is provided so that you can have supervisory control. Or you, as supervisor, can operate the joystick, while your child operates his/her switches. CooperCar allows your child to feel independent, *maybe for the first time in his/her life.*

OPTION

Wireless "child-enable" switch - \$125; for safety, self-esteem, and control assistance.

PRODUCT SPECIFICATIONS

Age/Weight range
Allowable adaptive seating
Batteries
Allowable switches

6 mo. to 60 lbs.
any insert should fit
rechargeable gel-cells
any with 1/8" jack



R. J. COOPER & ASSOC.
24843 Del Prado #283
Dana Point, CA 92629
(714) 240-1912

WHEELING FREE



MAXI

What You Should Know...

The Maxi is easier and quicker to roll and turn in a small space. Simple adjustments can fit the Maxi from child size to large adult in minutes at no additional cost. Seat height, width, depth and angle as well as fold-down back (including upholstery) can be adjusted for comfort and positioning in minutes. The foot bar is adjustable as is leg length and angle in seconds. Tilt-in-space is standard. Wheel camber is changed in seconds by hand providing lateral stability. Our three wheel-rear castor design provides unmatched stability. The Maxi is rigid for strength and modular for quick and easy transport. Total wt.: 25 lbs., Transport wt.: 14 lbs.

Want to Know More?
(714) 854-5355

Suggested Retail Price
Call for special discount

Why You Should Buy...

Expandability/Adjustability

Forty easy adjustments at no additional cost; including seat width, depth, height, angle; footrest length, angle; folding back height, angle; upholstery; wheelbase; wheel camber.

Durability

Advanced design and engineering using motorcycle and aircraft frame metals provides strength and light weight for a lifetime of care-free mobility.

Portability

Modular design with quick-release components and light weight allow easy transport in a small space.

Instruction Manual

Complete directions with illustrations and optional video to enhance use and adjustments.

Warranty and Service

Lifetime warranty on frame and one year warranty on wheels and upholstery. Service available at most wheelchair dealers and bicycle stores.

Unique Features

Two week free trial. Tilt-in-space standard. Wheel camber adjusts in seconds by hand. Three-wheel rear-castor design for unmatched stability and safety. Upholstery easily and quickly adjusts for comfort and positioning.

Colors

Frame has 14 colors including pearls and neons. Upholstery comes in 5 colors and two fabrics.

PRODUCT SPECIFICATIONS

Seat Depth	10" - 18"
Seat Width	11" - 17"
Back Height	10" - 18"
Weight Capacity	250+ lbs.
Total Weight	25 lbs.
Folds To Modular	11" x 12" x 12"

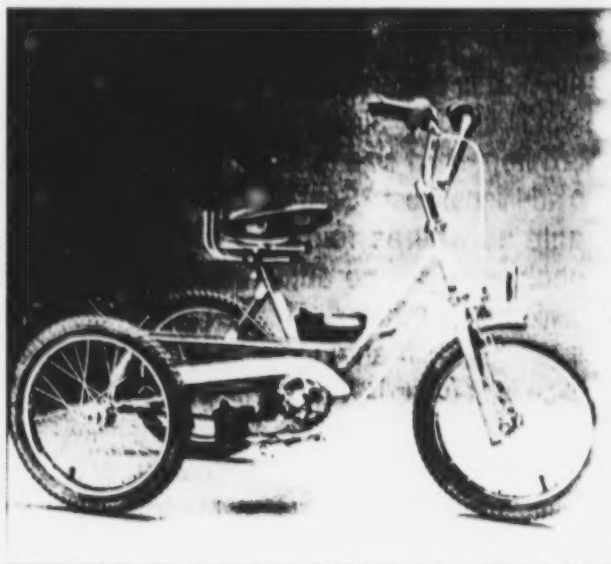
WHEELING FREE

6032 Sierra Siena
Irvine, CA 92715

(800) 484-9793 ext. 1600 (orders only)



TRIAID



What You Should Know...

TRIAID build tricycles which kids just love to ride. With sizes from 3 years upwards and a range of uniquely designed optional accessories to support and encourage, any child will benefit from their TRIAID trike.

A robust frame, wide wheel base, positive braking, extra wide saddle and our own unique steering stop ensure a safe and enjoyable ride. All trikes are supplied with our new super low gearing together with standard features such as pneumatic tires and direct drive pedaling to help get out of those tight spots!

Ease of use, adjustability and durability make TRIAID trikes ideal for use at home, school or hospital.

Want to Know More?
(301) 759-3525

Suggested Retail Price
Competitive Pricing

TERRIER / TMX

Why You Should Buy...

Appearance

Bright vibrant colors and ATB styling invite children to participate.

Adjustability

The trikes offer built-in adjustability so they literally grow with the individual.

Available options

Adjustable back/trunk support, pedal sandals with pulley system, padded abduction wedge, vertical handgrips, saddle bag, pelvic strap, control poles.

Durability

A specially designed welded tubular steel frame ensures maximum strength and rigidity.

Serviceability/Warranty

Full information and spares service available. Two year limited warranty on the frame.

Unique Features

Secure and stable riding position through our purpose designed adjustable back/trunk support and extra wide seat. Frame folding mechanism on the TMX Trike.

Colors

Terrier: Sky blue or pink

TMX: Royal blue or pink

PRODUCT SPECIFICATIONS

Steering head to saddle pillar	11"-13"	17"-19.5"
To suit inside leg measurement	17"-23"	22"-27"
Overall Width	28"	28"
Overall Length	41"	52"



TRIAID, INC.
P.O. Box 1364
Cumberland, MD 21502
(301) 759-3525

BRUNO

Independent Living Aids, Inc.



REGAL® PEDIATRIC

What You Should Know...

Your child benefits from superior lumbar, thigh and lateral support with Bruno's Adaptable Youth Seat, which features high resiliency, dual-density, anatomically correct foam bolsters. Seatback inserts provide attachment points for adaptive equipment. Exclusive E-Z TILT™ tiller and Slant Platform offer exceptional leg extension. Take-Apart Construction. Indoor or Outdoor use.

Want to Know More?
(800) 882-8183

PRODUCT SPECIFICATIONS

Seat	10"D/12"W
Back Height	15"
Frame Width	24 1/2"
Weight Capacity	250 lbs.
Total Weight	146 lbs., w/ Batteries
Drive Ratio	23:1
Max Climbing Angle	10°, 19% Angle
Motor	1.32 Peak HP, Efficient, Reliable 4 Pole Design

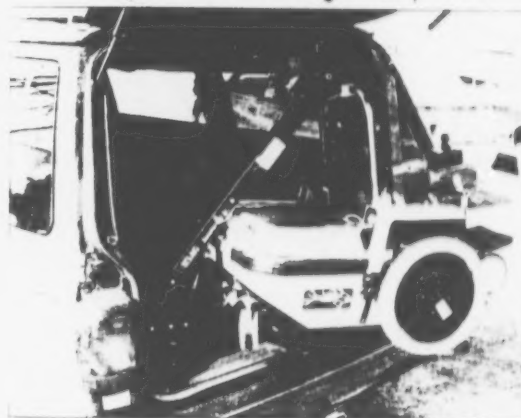
Suggested Retail Price
\$2,830



BRUNO INDEPENDENT
LIVING AIDS, INC.
1780 Executive Dr., P.O. Box 84
Oconomowoc, WI 53066
(414) 567-4990
(FAX) (414) 567-4341

BRUNO

Independent Living Aids, Inc.



VSL-550 SCOOTER-LIFT SR®

This is one of fourteen Bruno Lifts that can help you get your child's power chair, scooter or wheelchair in and out of most cars, vans, trucks or sport utility vehicles. Powered by your vehicle's battery and featuring single push button control, this versatile, rugged lift is easy to operate.

Want to Know More?
(800) 882-8183

PRODUCT SPECIFICATIONS

Weight Capacity	200 lbs.
Warranty	Fully Warranted
Availability	Worldwide Dealer Network
Manufactured in the U.S.A.	

Suggested Retail Price
\$1,122



BRUNO INDEPENDENT
LIVING AIDS, INC.
1780 Executive Dr., P.O. Box 84
Oconomowoc, WI 53066
(414) 567-4990
(FAX) (414) 567-4341

AMIGO



AMIGO MINI

What You Should Know...

The leader in customization for 25 years offers you the independent mobility your child needs for the best quality of life. The Amigo Deluxe Mini takes your child indoors and out, around tight corners and over outdoor terrain. Amigo's exclusive Touchtron handle puts all controls within reach. Your child is independently mobile at the park, in the backyard or at the mall.

Want to Know More?
(800) 248-9130

PRODUCT SPECIFICATIONS

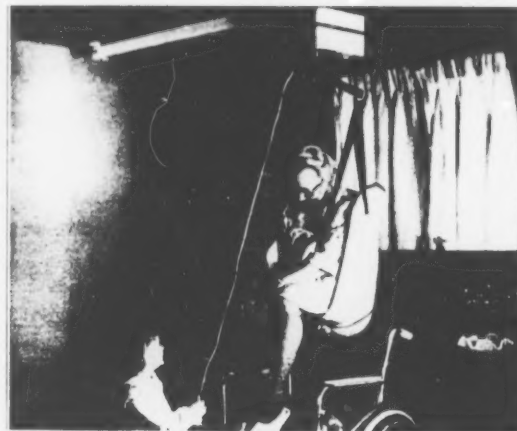
Seat Options	12-16 1/2"
Length	42.63"
Height	35"
Width	22.5"
Weight Capacity	350 lbs.
Total Weight	143 lbs.
Battery Capacity	30 miles

Suggested Retail Price
\$2995



AMIGO MOBILITY INT'L
6693 Dixie Highway
Bridgeport, MI 48722
(800) 248-9130

BARRIER FREE LIFTS



BARRIER FREE LIFTS

What You Should Know...

Barrier Free Lifts are: used independently, Many physically challenged people can transfer themselves unassisted. Multi-Directional, Vertical & horizontal motion at the push of a button. Air Tube Controlled, No electricity to the user! No chance of being shocked! Can operate while in water! Battery Operated & No Maintenance, Batteries can be automatically recharged.

Want to Know More?
(800) 582-8732

PRODUCT SPECIFICATIONS

Max. Load	350-400 lbs.
Max. Travel (up/down)	6.6'
Max. Speed	6-8' / minute
Charger	110 V/24V 1A
Battery	24 volt, D. C.
Max. Current	10 amps
Battery Capacity	24 V, 6.5 Ah
Warranty	12 months

Custom installations with variable pricing. Please call for estimates.



BARRIER FREE LIFTS, INC.
P.O. Box 4163
Manassas, VA 22110
(703) 361-6531 FAX (-7861)

CARRIE ROVER



THE CARRIE ROVER

What You Should Know...

Tumble Forms' Elementary Carrie Rover combines its Carrie seat for therapeutic positioning with the Rover Stroller base for mobility indoors and out. The redesigned Carrie Rover base is streamlined and lightweight with front swivel casters and oversized rear pneumatic tires. Seat may be used separately. Stroller base folds for storage. Four sizes. Crash tested for use on the school bus.

Want to Know More?
(800) 631-7277

PRODUCT SPECIFICATIONS

Seat Depth	10"
Seat Width	10"
Back Height	26"
Frame Width	22"
Weight Capacity	60 lbs.
Total Weight	40 lbs.
Folds To	12 1/2 x 22 x 30"

Suggested Retail Price
\$1,439

Preston
A BISSELL HEALTHCARE COMPANY

JA PRESTON
P.O. Box 89
Jackson, MI 49204
(800) 631-7277

BUDDY BUGGY



BUDDY BUGGY

What You Should Know...

As an exciting, inexpensive alternative to wheelchair outings for children with special needs, nothing outshines the BUDDY BUGGY. Its unique design gives you the freedom to explore areas not accessible in the past. An impressive array of special features makes the BUDDY BUGGY the top choice for fun transportation.

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(800) 458-7400

PRODUCT SPECIFICATIONS

Seat Depth	21 1/2"
Seat Width	30"
Back Height	21 1/2"
with handle	64 1/2"
Weight Capacity	120 lbs.
Total Weight	23 lbs

Suggested Retail Price
\$199 + Shipping & Handling



CLIFCRAFT
6400 E. El Dorado Circle
Tucson, AZ 85715
(800) 458-7400

SCOTT DESIGNS



SPECTRUM - STROLLER VERSION

What You Should Know...

Scott's Spectrum *Stroller Version* Wheelchair is so versatile, it has the capability to adapt to a child through years of growth, from infant to narrow adult. Canopy supports convert to armrests by adjusting them down the back posts. All aluminum, no weldmount frame, holds up to vigorous clampdowns on bus transport.

Want to Know More?
(800) 443-6663

PRODUCT SPECIFICATIONS

Seat Depth	Range fr 8" to 17"
Seat Width	Range fr 9" to 14"
Back Height	38"
Frame Width	12" to 14"
Weight Capacity	150 lbs.
Total Weight	25 lbs. w/ frame
Folds To	20" high, 31" long, 13 1/2" wide

Suggested Retail Price

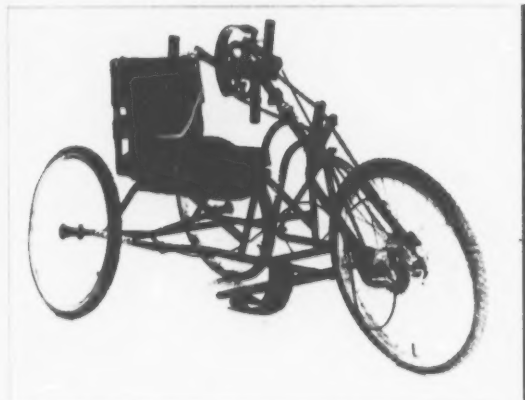
\$1,995 W/C Frame & Insert Mounting Hardware



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Livermore, CA 94550
(800) 443-6663

TOP END WHEELCHAIR

Sports, Inc.



THE JR. PRO-CYCLE

What You Should Know...

THE CRANK THAT CRANKS! A 35 lb. hand-powered vehicle constructed of 4130 Chromemoly. Custom adjustable frame and crank shaft, simultaneous power and steering, chain guard, internal reversing drum brake, and seat belt. For anyone with lower extremity weakness or paralysis! Two frame styles to choose from. Sized just for kids with 7 or 1 speed option.

Want to Know More?
(800) 532-8677

PRODUCT SPECIFICATIONS

Seat Depth	10-16" custom
Seat Width	10-16" custom
Back Height	8-16" custom
Frame Width	custom
Weight Capacity	200 lbs.
Total Weight	35 lbs.
Folds To	N/A

Suggested Retail Price
\$1795

TOP END
High Performance Wheelchairs & Bicycles

TOP END WHEELCHAIR SPORTS
4501 63rd Circle North
Pinellas Park, FL 34665
(813) 522-8677

•Lifts

Barrier Free Lifts, Inc.
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Manassas, VA 22110
(800) 582-8732

Ceiling Lifts are available in many models. The "Portable" can be transferred between different tracks. Lifts range from manual to fully motorized. Optional controls incl. non-electric air tubes & wireless radio controlled. Battery operated & easy to use, they lift, lower and move along a track.

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Oconomowoc, WI
(800) 882-8183

Manufacturer of a full line of lifts for powerchairs, scooters, and wheelchairs for cars, vans, or trucks. Call for free literature & dealer nearest you.

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14800 28th Avenue North
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Mfr. of wheelchair van lifts and hand driving controls. Have supplied adaptive equipment for the physically challenged since 1978.

The Flinchbaugh Co., Inc.
390 Eberts Lane
York, PA 17403
(800) 326-2418

Ricon
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Pacoma, CA 91331
(800) 322-2884

Mfr. of mobility equip. for personal & commercial vehicles. Electric/electro-hydraulic wheelchair lifts, power door operators & 6-Way Power Seat Bases.

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Evergreen, CO 80439
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Air Lift's backpack lets YOU carry your infant's oxygen. It gives you freedom to hold and cuddle your baby. Sturdy, comfortable, attractive and non-flammable. Lightweight backpacks also available for children. Please call for additional information.

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Mundelein, IL 60060
(800) 876-RAMP

The world's oldest manufacturer of quality, low-cost ramps and tracks. Call "THE RAMPSMITHS" for a free quote or brochure.

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Kent, WA 98042
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(800) 458-7400

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Dana Point, CA 92629
(714) 240-1912

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All-terrain stroller fits children of many sizes. Affordable, lightweight, durable. Models from Baby Jogger to XL Special Needs II. Adaptable for seating inserts.

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A universal wheelchair and occupant restraint system. Every component is designed, engineered and tested to work together to prevent passenger injury in a collision. If you are responsible for safety, Q'Straint puts that safety as the single most important priority.

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"Regal" battery operated RWD three-wheel scooter with custom adaptive seating for the pediatric rider. Call for free literature and dealer nearest you.

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Convaid Products, Inc.
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Compact-folding, lightweight positioning buggies for all ages, three sizes, three colors, over 20 positioning features. Five year warranty.

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MOBILITY BUYERS' GUIDE

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Santa Paula, CA 93060
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(416) 841-1032

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The Merry Walker

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Northbrook, IL 60062
(800) 827-8318

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Fresno, CA 93722
(209) 276-0991

Quickie Designs, Inc.

2842 Business Park Avenue
Fresno, CA 93727
(800) 456-8168

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Mobile Stander safely and comfortably mobilizes a child in an adjustable, upright position. Choice of three sizes fit toddlers to teens up to 60". Lightweight aluminum construction. Adaptable and adjustable. Choice of activity tray or positioning tray. Please call or write for more information.

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EnterVan, a lowered floor Chrysler minivan with a folding ramp. The EnterVan is the perfect choice for growing families.

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Phoenix, AZ 85017
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(800) TDD-0312

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(800) 323-9935

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Battle Creek, MI 49016
(616) 964-7727

Mini van for wheelchair or scooter transportation. Eliminates entry problems, uses all electronic controls, no hydraulics to contend with; economical.

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(800) 367-6567

KNEELKAR™ lowers near to ground level to let you in. The ramp folds down to meet you. Remote control available. Call for more information.

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J.A. Preston

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Jackson, MI 49204-0089
(800) 631-7277

Tumble Forms' Carie Rover's redesigned base is streamlined, lightweight. Rides comfortably indoors & out.

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Santa Paula, CA 93060
(805) 525-7165

Quickie Designs, Inc.

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2169 Las Positas Court, Suite C
Livermore, CA 94550
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Scott Spectrum has the capability to adapt through years of growth from infant to narrow adult. Seating systems designed to each individual.

Top End Wheelchair Sports, Inc.

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Pinellas Park, FL 34665
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The Predator is a 35lb. hand powered vehicle constructed of 4130 Chromemoly and painted in your choice of 30 colors. Two frame styles to choose from. Our Jr. Predator is sized just for kids with 7 or 1 speed options. Please call or write for more information on The Predator.

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The Maxi features three-wheel rear castor design for stability, quick turning in a small space and easy rolling. Tilt seat. Width adjustment 11" to 22". Camber by hand in seconds. Capacity: 250+ lbs. Weight: 25 lbs. Please call for more information.

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DAMACO Freedom on Wheels

20542 Plummer Street
Chatsworth, CA 91311
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Electro-Lite power and Enabler manual wheelchairs seat widths and depths range from 12" to 15". Expandable for growth.

Electric Mobility

1 Mobility Plaza, Dept. 3600
Sewell, NJ 08080
(609) 468-0270

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2842 Business Park Avenue
Fresno, CA 93727
(800) 456-8168

Mfr. of high quality, custom wheelchairs, offering a variety of manual wheelchairs, power wheelchairs, and seating & positioning products.

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(603) 623-5679

Power/Manual wheelchairs, child-adult, Quickie, Invacare, others avail., demos. LPN/OT on staff to assist with proper fittings. Trained techs., service dept.

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N. Hollywood, CA 91605
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Complete car, mini-van and full size van modifications, sales and services for drivers and passengers. Operated by a Biomedical Engineer since 1975.

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Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

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Full-size/Mini-Van modifications, new/used, lifts, dropfloor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

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Dayton, OH 45404
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We do it all! The most complete line of services in New England. Please call or write for more information at (603) 623-5679.

•Michigan

Handicapped Driving Aids of MI
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Wayne, MI 48184
(313) 595-4400

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HDS
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Bloomington, MN 55420-2735
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Sales, installation & service all.
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Arcola offers the widest selection of full-size and mini-van conversions, wheelchair lifts, and adaptive driving equipment.

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Forward Motions, Inc.
214 Valley Street
Dayton, OH 45404
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Full-size/Mini-Van modifications, new/used, lifts, dropfloor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

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Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

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WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY

by Marilyn Lash, M.S.W. Published by *Exceptional Parent*, in collaboration with the Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center, ©1992 Tufts University. For information about purchasing *When Your Child Goes to School After an Injury*, please see ad on page 37.

The following excerpt is from the chapter Getting to and from School Safely by Kim Hesse, M.S.W.

Many parents fear their child will be hurt again. Since car crashes are a major cause of first and repeated injuries, this chapter discusses prevention methods for safe transportation. When your child returns to school, many different people, including relatives, friends, school bus and special van drivers, may be transporting your child. Transportation is a related service that can be part of your child's educational plan if special care is needed.

Every state has a child safety law. Since each state is different, check with your Governor's Highway Safety Office for the law in your state.

Questions to Ask the School About Transportation

- How will my child travel to and from school?

- How do I know my child will be safe between home and school?

- How can I be sure the person driving my child is sensitive, reliable and cautious?

- Who will meet my child after arriving at school?

- Who will meet my child after returning from school?

- How will I know if there is a problem when I'm not with my child?

- Is there an emergency plan for my child during travel?

What If My Child Uses a Wheelchair or a Special Van?

Special measures must be taken when children travel in wheelchairs. Very often they use a special van or transportation company arranged through the school. Below is a checklist for your child's safe transportation in a wheelchair.

- What kind of training in first aid and emergency procedures has the driver received?

- Does the driver wear a safety belt?

- How does the transportation company conduct regular checks on motor vehicle offenses by their drivers?

- How much information is the driver given on your child's condition and special needs?

- How often do the drivers change?

- Will other children be transported with your child and how many?

- Have you inspected the inside of the van for cleanliness, neatness and stored emergency items?

- Are there loose items that could fly around and hit your child during a sudden stop or crash?

- Does the exterior of the van look well maintained?

Some parents have found that special transportation isolates their child from schoolmates. No matter how chaotic, riding the school bus is a social activity. So is walking home with friends. When the children with special needs are separated for special transportation services, they may feel "different" than their

classmates. This may happen again after arriving at school if a child has to use a different entrance at the side of the building for a ramp or railing. Parents suggest working out a plan with the school so that a classmate or aide meets your child upon arriving and leaving.

Another concern of parents is the need to have a backup system in place. Emergencies, delays, changes in plans or routes, and mixups happen sooner or later. Your child, family, school, and the driver and transportation company all need to have a written plan for who is to be contacted in case of changes or problems. More than one person should be listed as a backup in case the first is unavailable.

Safety Rules for Wheelchair Transportation

Standard wheelchairs are not designed to be transported in motor vehicles, so special precautions are needed.

- A system to hold and secure the chair to the vehicle should be required and meet crash test standards of experts. It is best to secure the wheelchair to the vehicle at four different places. This is called a "Four point tie-down system." Ropes, large elastic cords, or blocks of wood are not safe and should *never* be used.

- A restraint system must be used to hold the child safely in the chair. This should be a shoulder and lap belt that states it has been crash tested for use with wheelchairs in motor vehicles. Positioning harnesses and velcro are not safe protection during travel. Lap trays must be removed. The child should have head or neck support.

- Wheelchairs must face the front or rear of the vehicle, never the side. A side-facing wheelchair can collapse in a crash.

- Any equipment or supplies (oxygen tanks, braces, walkers, crutches) must be placed under the seat or on the floor surrounded by pillows to limit movement in case of a crash.

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The following excerpt from Chapter 5: Equipment has been reprinted with permission from the publisher.

Many children with specific health care needs use special equipment for many months or years. Families can usually learn to manage this equipment, even though the idea may seem overwhelming at first. After discharge, your child's equipment needs may be taken care of by the home care agency or a separate equipment vendor. As you go along, other parents and professionals may give you advice or suggestions about other systems or a particular product or brand. You should feel free to discuss these questions and any other concerns with your equipment supplier or a member of your child's health care team.

How do I learn about my child's equipment?

Learning about the equipment should begin early on in your child's

hospital stay. As soon as your child has a discharge date, the appropriate equipment will be determined and should be ordered and set up before your child leaves the hospital. You and your child's discharge planner should set up home training dates; usually the home care agency or equipment vendor will do the actual training. Training should be done on the same type of equipment that you will be using.

By the time your child leaves the hospital, all the equipment should be in proper working order and you should be comfortable with how it works. It is helpful to ask that your child be discharged from the hospital early in the day so that you have plenty of time to get your child and his/her equipment settled upon returning home.

What are my responsibilities regarding my child's equipment? What are the equipment supplier's responsibilities?

Parent:

- checks each equipment delivery for proper product, size and amount
- keeps a list of all supplies with item or order number
- checks supply levels weekly and orders supplies in advance
- does basic, routine cleaning and informs the supplier of any maintenance problems, whether the equipment is rented or purchased
- sends in the warranty information if you own your equipment
- if lives in a rural area, requests backup equipment for emergencies

Equipment supplier:

- delivers, installs and checks the operation of any new equipment
- demonstrates and teaches proper care, maintenance and operation
- leaves instructions for care and cleaning
- has a staffed 24-hour service number
- provides backup equipment while the regular equipment is being repaired

- services rental equipment to factory standards
- may have professional staff available for training, information and questions

Who will pay for my child's equipment at home?

Possible sources for payment are:

- private insurance companies, including HMOs
- Medicaid and other public programs
- parent's co-payment
- community, civic and religious groups
- disability organizations

What are the advantages ... of renting versus owning equipment?

Advantages of renting:

- equipment supplier will maintain, repair and perform major cleaning of equipment, though there may be a charge for these services
- easier to change to the most up-to-date equipment
- your child's need for the equipment may only be short-term or it may be something s/he will quickly outgrow

Advantages of purchasing:

- can be less expensive over time
- you may be able to purchase used equipment

Sometimes, the advantages of one method over the other are not so clear. For example, in some cases, insurance companies may pay for the repair of equipment, even when it has been purchased.

More importantly, the decision to own or rent equipment may be made by your insurance provider. In some instances, you may be able to convince your insurance provider about the merits of one method over the other. Your doctor can write a letter to your insurance provider to advocate rental or purchase of certain pieces of equipment. In other cases, insurance companies may have certain guidelines they must follow.

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Bruno	29-55	Life Enhancement Products	51
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Citcraft Manufacturing, Inc.	57	Mobility Tech. Corp.	39
Columbia Medical	7-9, 41	Mulholland	23
Consumer Care	40	Nesheeka	39
Convaid	20-48, 49	New England Villages	89
Cotting School	88	Plum Enterprises	1
Crow River	71	Prime Engineering	45
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Information from The National Parent Network on Disabilities

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CONTENTS:

NPND Policy Statement	67
Hawkins Steps Down	68
Executive Director's Report	69
Multiculturalism and Disability	70

NPND Policy Statement on Education Reform

During the NPND Annual Meeting, the membership and the Board of Directors crafted a policy statement regarding the anticipated legislative activity concerning education reform. The statement below, is a brief expression of the NPND position on education reform. Please reprint this statement in as many newsletters as possible. Additionally it is critical that parents across the country begin to organize and mobilize to effectively participate in education reform at both the state and federal level.

In order to assure that every child in the country realizes their greatest potential and achieves the life role of their dreams, we recognize the urgent need to reform the public education system in this country. We are ready to commit our full energy, resources and spirit and to strive for more positive educational outcomes for all children.

As parents of children who participate in both regular and special education programs, we are in the unique position of experiencing and valuing both. Based on our eighteen years of experience with what is now known as IDEA, we are committed to the belief that the protections embodied in that law are critical to assuring that all children receive a free, appropriate public education. We, therefore, urge that the basic tenets of IDEA be viewed as a model for the education of all children. Minimally, we affirm our commitment to IDEA, oppose any revisions to it, and urge that its basic tenets be applied to the reform of regular education.



Out going President Connie Hawkins congratulates New President Diana Cuthbertson.

Cuthbertson Heads New NPND Board

On January 25, 1993 the NPND membership elected a new Board of Directors. The new members are:

Joan Kilburn, San Rafael, CA
Sweet Alice Harris, L.A., CA
Kathy Erickson, Minot, ND
Bonnie Johnson, Little Rock, AR

On January 27, 1993, the NPND Board of Directors elected their new officers. They are:

Diana Cuthbertson, President
Joanne Butts, Vice President
Sue Pratt, Vice President
Christine Davis, Treasurer
Pam Steneberg, Secretary

Information On Education Reform Needed

Education reform has been occurring at the state level for the last several years. Anecdotal reports of activity at the state level have begun to pour in. In most cases, the news has been alarming. As the federal discussion of education reform begins with the new administration, it is imperative that the experiences of grass root parents be heard. Please send NPND any information that you have concerning the education reform activities that are occurring in your state. No piece of information is too small or inconsequential. We need to paint an accurate picture of the realities of educational reform for the policy makers here in Washington. They are asking for this type of information. Time is of the essence. Please forward any and all information to the attention of Larry Searcy at NPND or call him at (703) 684-6763.

INFORMATIONAL FORUM

NPND Shirt Now Available

The coming year promises to be full of critical legislative and policy activity that will impact upon families of children and adults with disabilities all over the country. In order to carry your message forward, NPND needs financial support that is not tied to federal grants or contracts. Please help support NPND in carrying your message to Congress and get a nifty tee to boot. Now at the low, low cost of \$15 you can have your very own NPND tee shirt emblazoned with the NPND logo. Shirts are available in royal blue, hot pink, white, and red. In all but the hot pink, shirts are available in large, x-large, and xx-large. Hot pink is available in only large and x-large. Let folks know where you stand. Get Teed off!!!! Get an NPND tee today!!!!

Hawkins Steps Down

Connie Hawkins, who serves as the Executive Director of ECAC in North Carolina and for the last three years served as the president of NPND, declined to run for the presidency for another two-year term. Hence, with the election of the new NPND officers on January 27, 1993, her term as president came to an end. During her term, NPND has developed into the national voice for parents for which it was originally conceived.

Throughout her term, Ms. Hawkins, in addition to the usual duties of president, also represented NPND at national meetings. She most recently represented NPND at the National Education Reform Forum in Charlottesville, VA. Fortunately, Ms. Hawkins will continue to serve on the NPND Board of Directors and will be

available to assist Diana Cuthbertson, the new NPND president, in the discharge of her office.

Update of Membership

Update on the membership of the NPND as of October 30, 1992:

Parent Coalitions — 76 Individual — 211
Parent Groups — 27 Professional — 62
Affiliated Organizations — 28

New Groups

Affiliated Groups — Center for Disability & Socioeconomic Policy Studies, 2900 Van Ness St., NW, Washington, DC 20008, 202-806-6100

Institute of Community Integration, University of Minnesota, 150 Pillsbury Drive, SE, Minneapolis, MN 55455, 612-624-5005

Community Development Annandale Village, 3500 Annandale Lane, Suwanee, GA 30174, 404-945-8381

Toward Maximum Independence, 9370 Sky Park Ct. Suite 250, San Diego, CA 92123, CA 92123, 619-467-0600

Parent Groups — Let's Face It, Inc., P.O. Box 711, Concord, MA 01742, 508-371-3186

Exceptional Family Resource, 731 James St., Suite 302, Syracuse, NY 13203, 315-478-1462

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Mission:

The National Parent Network on Disabilities (NPND) was established to provide a presence and national voice for parents of children, youth, and adults with special needs. NPND shares information and resources in order to promote and support the power of parents and resources to influence and affect policy issues concerning the needs of people with disabilities and their families.

Membership Fees

Parent Coalition - Voting	\$ Sliding
(Call NPND for details)	Scale
Affiliated Organization	100
Parent Group	50
Parent/Individual with a Disability	25
(Stipend Avail.)	
Professionals	40
Contributor	1,000
Corporation	1,000
Sustaining	3,000

☒ I/we would like to join the NPND.

Name

Organization

Address

City

State

ZIP

Home Number ()

Work Number ()

Please return this form with your check made payable to: The National Parent Network on Disabilities, 1600 Prince Street, Suite 115, Alexandria, Virginia 22314, (703) 684-6763.

EXECUTIVE DIRECTOR'S REPORT

by Patricia McGill Smith

Annual Meeting

On January 25, 1993 NPND held its third annual meeting. This year the meeting convened at 9 a.m. rather than noon as the NPND Board of Directors held its meeting on Sunday instead of Monday morning.

This year's meeting was especially well-attended. 125 persons were in attendance when President Connie Hawkins called the meeting to order. The early morning was spent conducting Network business. Hence, each of the NPND standing committees reported to the membership, floor nominations for the Board election were taken and each nominee introduced themselves to the membership.

Prior to the reports of the standing committees, Connie Hawkins gave the President's report. Following the Standing Committee Reports, Patricia McGill Smith gave the Executive Director's Report in which she detailed the NPND Annual Report for 1992 (Available on Request).

Following the business session, the meeting focused on education reform. After much discussion and small-group consensus building, the NPND membership reported on the issues that they felt were critical to NPND's position regarding national education reform.

Early in the afternoon, Bob Griss of United Cerebral Palsy Association gave a brief presentation and led a discussion on the issues surrounding national health care reform. He was followed by Linda Hinton of Senator Harkin's staff and Lawrence Peters, chief counsel to the House of Representatives Select Committee on Education, representing Maria Cuprill, chief of staff for Rep. Major Owens. They discussed the upcoming session of Congress and responded to questions from NPND members.

Later that evening in conjunction with the NPND Silent Auction,

NPND honored Dr. Douglas Biklen and Betty Pendler for their contributions to the field of providing services to persons with disabilities and their family members.



Douglas Biklen



Betty Pendler

Betty Pendler is a parent leader from New York who has exemplified the power of one parent. Betty has been a writer, lecturer and policy maker for more than thirty years. She is noted for her good humor and straight talk for parents. Her outspoken advocacy is noted for telling persons with disabilities the truth about all phases of life. She was one of the first to speak out about issues concerning sexuality. Widowed early in life, Betty has successfully raised her son and daughter who have each led their own lives. Echoing the nationally famous Betty Pendler toast, "Here's to Betty, she's terrific."

Accepting the award for Betty were Marge Goldberg and Paula Goldberg, PACER Center, Minneapolis, Minn.

Dr. Biklen is the Director of the Facilitated Communication Institute at Syracuse University in Syracuse, New York. He has worked his entire career to advance the field of education with an emphasis on special education. Currently, Doug is a faculty member at the School of Education at Syracuse. NPND cited the major contribution that Dr. Biklen made as the Executive Director of the award-winning film, "Regular Lives." Dr. Douglas Biklen was honored for the courageous leadership he has provided in the development of facilitated communication for persons with autism and other communication disorders. Nancy Deel, a Tennessee parent with firsthand knowledge of the success of

facilitated communication, accepted the award for Doug.

Legislative Update

The last year was a highly successful one on the legislative front. As you know, the Rehabilitation Act was reauthorized and NPND was a major player in assuring that a consumer board be put in place in each state to review and have input into each state rehab plan. Provisions for "choice" demonstration programs were established and training programs for parents and other family members were created. All in all the Rehab Act is now a lot more "user friendly." NPND is proud to have been part of the coalition that made it possible.

Additionally, work that NPND carried out long ago finally paid off with the passage of the Family Medical Leave Act. While it still falls short of the type of support families of children with disabilities need, it's a huge step forward in legitimizing the role of parents in caring for their children, and assigns some level of the "right" to do so. This act will be profiled in more detail in a future Networking.

Healthcare Reform

As rewarding as the last year has been, the coming year promises to be equally challenging. Health care reform is on a fast track. The concerns of persons with disabilities and their families are not at the forefront of the current health care deliberations. To respond to the fast moving conceptualization of a national health care reform movement, a national grassroots organization has been established. Known as Family Voices, this organization is actively constructing a health care reform agenda that includes disability. NPND has participated in the activities of this group and will continue to cooperate with them. For further information about Family Voices, contact Betsy Anderson at CAPP project in Boston. She can be reached at (617) 842-2915.

continued on page 70

continued from page 69

Motor Voter

It appears the "Motor Voter" bill will again take on life during this session of Congress. NPND will support this legislation to assure that persons with disabilities have an equal opportunity to register and vote.

Passage of the Family and Medical Leave Act

On February 5th 1993, President Clinton signed into law the Family and Medical Leave Act. Under the provisions of this act employers of 50 persons or more are obligated to provide up to 12 weeks of leave to their employees to provide care to family members. While this "leave" is unpaid, it does assure that the employee can return to his/her job at the end of the leave period.

The NPND has been active in advocating for the Family and Medical Leave Act (FMLA) since its inception several years ago. If nothing else the FMLA demonstrates that good ideas are never defeated, only delayed.

Multiculturalism and Disability

The word multiculturalism has become a buzz word lately gaining wide recognition in most fields, yet how the term has been interpreted varies greatly. Multiculturalism is often understood as simply the study and understanding of a variety of ethnic groups with the belief that by studying their different characteristics

and traits we (the dominant culture) will be better able to work together with these differences (Suzuki, 1984).

Many, however, believe that taking a multicultural perspective means going beyond this sole focus and looking at the other social forces that shape our lives (Banks & McGee Banks, 1989; Gollnick & Chinn, 1990; Goodenough, 1987). In this view, multiculturalism includes the study of the effects of race, culture, class, gender and disability to name a few. A multicultural perspective then provides a way of understanding ourselves and encourages all of us to look at how our own values and perspectives affect our view of the world and influence how we interact with those that are different from ourselves. It also acknowledges the existence of a dominant culture, characterized by what can be called white, middle-class assumptions and behaviors.

Within our educational and human service system differences in race, culture, class and gender among other things, all affect how families and people with disabilities are served and the decisions that are made about their lives. As we are increasingly learning the importance of listening to parents and people with disabilities, multiculturalism is providing a framework to begin to listen to people who have been discriminated against

not only for their disability, but a number of other factors that play an important part in their identities. A multicultural perspective also challenges us to acknowledge the power differential that keeps racism, sexism, handicapism and classism alive in this country.

Recognizing the strengths that people have because of a perceived difference and understanding the value judgements we all have because of who we are is integral to a multicultural perspective. What have often been perceived as deficiencies by the dominant culture are rather strengths and survival techniques for people who have been discriminated against because of their race, gender, disability, class or culture.

Multiculturalism is not a new concept but given the changing demographics in our country and the long histories of oppression that so many people have endured, issues being raised through multiculturalism offer us another chance to begin to understand and work together recognizing that we are all part of the problem and the solution.

For a list of References and Select Resources please contact: NPND 1600 Princet Street, #115 Alexandria, VA 22314.

by Susan O'Connor, Center on Human Policy, Syracuse University

Family Support National Conferences

To register or get an agenda, please contact
Barbara Raab

April 16 & 17, 1993

Marriott Hotel, Berkeley, California
and

May 21 & 22, 1993

Marriott Hotel, Albany, New York

HSRI

2336 Massachusetts Avenue
Cambridge, Massachusetts 02140
(617) 876-0426

Networking is information from the National Parent Network on Disabilities. The Network is a membership organization open to all agencies, organizations, parent centers, parent groups, professionals, and all individuals concerned with the quality of life for people with disabilities.

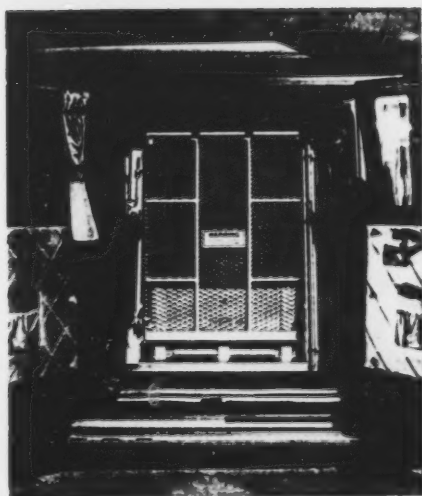
Patricia M. Smith
Executive Director

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Hearing Aid Bank Offers Free Devices

Hear Now has established a National Hearing Aid Bank (NHAB) to provide free, reconditioned, behind-the-ear hearing aids to individuals who are financially unable to purchase new hearing aids.

NHAB accepts donations of used hearing aids, reconditions them and distributes them to those in need. Donors receive a \$100 tax receipt for each hearing aid.

People who want an NHAB hearing aid must fill out an application and contribute some amount toward the purchase if possible.

Hear Now is a national nonprofit health organization dedicated to helping individuals with limited financial resources who are deaf or hard of hearing.

For more information, contact Hear Now, (800) 648-HEAR.

Neuromuscular Disease Referral Program Formed

The Muscular Dystrophy Association (MDA) and the Shriners Hospitals for Crippled Children have formed a mutual referral program to augment medical care for children with neuromuscular diseases.

Under the Partners in Service program, directors of MDA's 235 clinics can refer young patients who need orthopedic surgery to any of the 19 orthopedic hospitals operated by the Shriners organization. The hospitals offer free orthopedic surgery to financially needy patients under age 18.

Similarly, the staff at the Shriners facilities can refer children with neuromuscular diseases to MDA clinics across the country for a range of services, including durable medical equipment such as wheelchairs and braces.

The MDA provides these services at no cost, regardless of the family's ability to pay.

Society Addresses Communication Needs in the U.S.

More than one million persons in the United States have such severe expressive communication disorders that they are unable to meet their communication needs through speech and/or writing.

In October 1988, a U.S. chapter of the International Society of Augmentative and Alternative Communication (ISAAC) was formed to help address those needs. The mission of the U.S. Society for Augmentative and Alternative Communication (USSAAC) is to enhance the communication effectiveness of persons who can benefit from augmentative and alternative communication (AAC) through areas of public awareness, public policy, education and research.

The specific purpose of the USSAAC is to:

- Influence national and state public policy and legislation.
- Assist individuals in their right to communicate, allowing full participation in society.
- Disseminate legislative, regulatory and funding information.
- Promote public awareness.

- Promote transdisciplinary professional education.
- Facilitate quality service delivery.
- Foster local, state and regional activities.
- Compliment and support ISAAC goals and activities.
- Work with other organizations serving the interests of AAC system users.

The USSAAC is an organization for professionals, families and AAC system users alike. It provides a mechanism for information exchange and focuses attention on work being done to help people with communication difficulties.

The USSAAC also provides an opportunity to have a voice in national issues, promotes state activity organization, sponsors conferences and workshops, publishes a quarterly newsletter and entitles members to reduced subscription rates on several publications.

For more information, contact Theresa Saldana, Administrative Assistant, Fountain Valley School District, 17210 Oak St., Fountain Valley, Calif. 92708. (714) 843-3278.

Braille Children's Anthology Available Free of Charge

Braille Institute has announced the publication of Volume 44 of *Expectations*.

This annual anthology of contemporary children's literature is published in Braille grade II by the Institute's Braille Press and distributed throughout the United States and 40 foreign countries. *Expectations* is

given free to blind children attending grades three through six.

Complimentary copies are also sent to parents, teachers, service agencies, schools, libraries and other organizations that use the book's stories, poems, embossed illustrations and "scratch-and-sniff" labels to encourage and enhance literacy among children who are legally blind.

Contributions from individuals and organizations help significantly in funding the cost of printing and distributing about 3,000 copies of *Expectations* each year. Donations are not required to receive copies of *Expectations*, but they are always welcome.

For more information, contact Braille Institute, 741 N. Vermont Ave., Los Angeles, Calif. 90029, Attn: Douglas Menville.

ORGANIZATION NEWS

Closed

• **IBM National Support Center for Persons with Disabilities**, Atlanta, GA. The center's resource guide for persons with mobility impairments is available through state vocational/rehabilitation agencies.

Moved

• **The Sibling Information Network**, A.J. Papanikou Center, 1776 Ellington Rd., South Windsor, CT 06074, (203) 648-1205.

New Newsletter

• **The Myelin Messenger**, c/o Ruth Anderson, HC-29, Box 686, Stable Ln., Prescott, AZ 86301-7435.

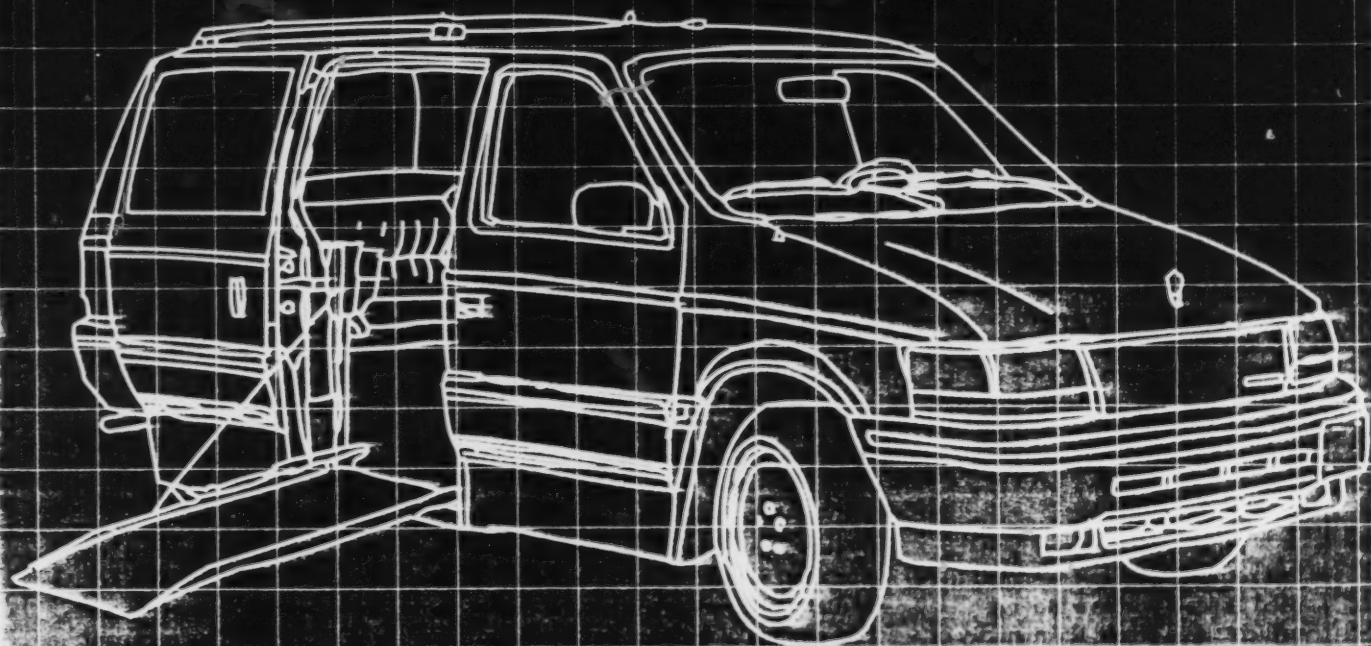
New Support Groups

• **Chromosome Deletion Outreach**, c/o Christine Barr, P.O. Box 164, Holtsville, NY 11742.

• **National Aphasia Association Young People's Network**, P.O. Box 1887, Murray Hill Station, New York, NY 10156-0611, (800) 922-4622.

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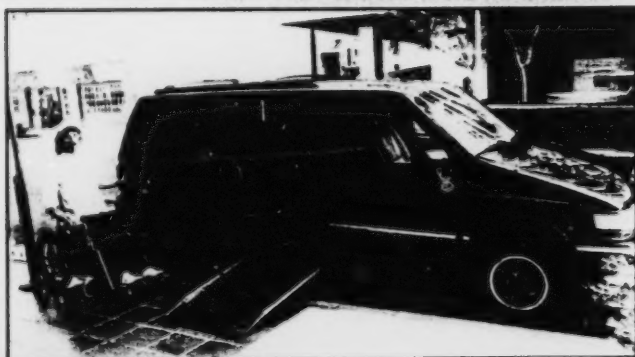
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School Bus Safety Dispute

Increasing numbers of children with disabilities use existing wheeled mobility devices (WMDs) such as wheelchairs, scooters, strollers, powered bases, etc. as a means of accessing both public and personal vehicles. For most, the ability to use their WMD while riding in a transportation vehicle is the only feasible means of gaining access to educational or recreational activities.

Most WMDs currently in the marketplace were not designed to be used as seats within a moving vehicle. As a result, the majority of them do not have designated and tested attachment points for securement in the vehicle, and they cannot be easily or effectively secured to withstand the forces of a crash. Most WMDs will therefore not provide the occupant the same level of safety as that provided by auto and bus seating. This reality creates a safety concern for both the WMD occupant as well for other passengers in the vehicle in the event of a crash situation.

Often, children cannot transfer from their WMD to a regular bus seat and must be transported in their WMD because it contains a specialized seating insert custom-made for the individual. In recent years there has been an explosion in the number of WMDs and seating systems being used.

Essentially, none of these devices has been developed and tested for use as a seat in a transport vehicle

because no testing standards exist. Therefore, children are being transported in devices that may be unsafe for transport use.

Most recently, representatives of the pupil transportation organizations have been informed by representatives of the wheelchair industry that stickers will start appearing on WMDs notifying purchasers to this effect.

Another concern is the method by which the WMD is secured to the transport vehicle. A small industry of manufacturers produces and markets a range of restraint devices now used in most school buses, paratransit and personally licensed vehicles to secure existing WMDs. Representatives from this industry have been participating as members of a multidisciplinary task group to develop a national performance standard for restraint devices. This work is almost complete. Completion of the standard, followed by compliance within the industry, will yield a nationally recognized level of restraint device safety performance.

Push for Standards

For several years, many individuals and organizations concerned about the safe transportation of students who need special seating equipment attempted to have the National Highway Traffic Safety Administration (NHTSA) amend Federal Motor Vehicle Safety Standard (FMVSS) 222 to include safe seating standards for students with

disabilities. FMVSS-222 currently provides safe seating requirements for students without disabilities on school buses, but specifically excludes students with disabilities from that standard.

The lack of a seating standard that addresses the safe transportation of students with disabilities is a primary concern facing both transporters and parents of children requiring special transportation accommodations. The desired standard would include requirements for WMD crash worthiness, specifications for securing the WMD (including occupant protection) and instructions regarding the secured orientation of an occupied WMD in a school bus (forward-facing, rear-facing, etc.).

Response to 504 Complaint

In July 1989, Lyle Stephens, C.E.O. of Dean Transportation, Inc., and Debra Simms filed a discrimination complaint with the U.S. Department of Transportation, National Highway Traffic Safety Administration (NHTSA), concerning school bus seating for students with disabilities. They alleged that the NHTSA had violated section 504 of the amended Rehabilitation Act of 1973 by failing to establish "school bus passenger seating or crash protection requirements for handicapped students who use wheelchairs or require devices other than the traditional school bus passenger seat while being transported."

On Jan. 15, 1993, having
continued on page 76

FAMILY MATTERS



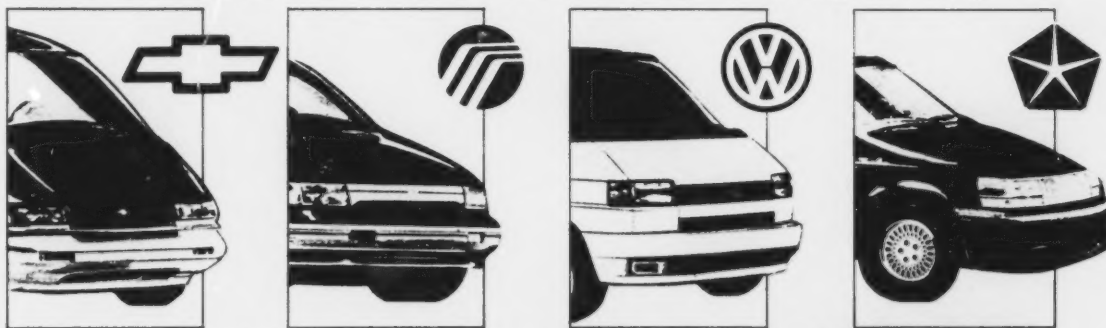
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continued from page 74

completed the required review process in order to respond to the complaint, NHTSA published a final rule in the Federal Register (Vol. 58, No. 10, pages 4586-4599):

"This final rule amends Standard No. 222, School Bus Passenger Seating and Crash Protection. School buses designed (on a voluntary basis or pursuant to a legal requirement other than one issued by this agency) to transport persons in wheelchairs will be required to be equipped with wheelchair securement devices and occupant restraint systems meeting specified performance requirements. Among the performance requirements are ones regarding location and minimum strength for the anchorages of those devices and systems and ones regarding minimum strength of the devices and systems themselves.

"This amendment will complement existing provisions in Standard No. 222 specifying occupant protection requirements for school bus passenger seating and restraining barriers. This amendment will provide a level of occupant protection for students in wheelchairs as comparable to that currently provided to persons able to use standard bench seats as is practicable. In addition, this amendment will prevent potential injuries to all occupants that could be caused by an inadequately secured wheelchair." (from Summary)

Petition for Reconsideration Filed

On Feb. 1, 1993, Mr. Stephens filed a Petition for Reconsideration with the administrator of the NHTSA. Here are excerpts from the petition's summary:

"1. NHTSA, in amending FMVSS-222, has ignored the safety of handicapped students when seated in wheelchairs and mobile seating devices on a school bus, by failing to establish safety standards for other than bench seats on a school bus.

2. NHTSA, by failing to establish safe seating standards for wheelchairs and other mobile seating devices, and failing to mandate the

use of securement and occupant protection equipment, has increased the risk of injury to students riding the same school bus with handicapped students using mobile seating.

3. NHTSA has failed to provide comparable safe seating for handicapped students to the same extent as non-handicapped students by claiming a lack of authority to regulate wheelchairs. Wheelchairs are not the issue. Seating is the issue, and is clearly within the jurisdiction of NHTSA, regardless of whether the seat is stationary or mobile, when used as a seat on a school bus.

4. In amending FMVSS-222, NHTSA has failed to extinguish the claim of discrimination cited in the 1989 Section 504 complaint ..."

In closing, Stephens urged that "NHTSA reconsider its action by withdrawing the final rule and take action to:

a) establish mandatory performance standards for the use of mobile seating on school buses comparable to that for bench seating on school buses; and

b) make the use of approved wheelchair securement equipment, occupant protection equipment, and forward-facing seating for all seated passengers on a school bus mandatory."

This controversy will be a major topic of discussion at the Second National Conference on Transporting Students with Disabilities in Atlanta, Ga., in early March. We plan to keep readers informed.

Special thanks to Lyle Stephens, C.E.O., Dean Transportation Inc., Lansing, Mich., and Douglas Hobson, Ph.D., Rehabilitation Technology Program, University of Pittsburgh, Pittsburgh, Penn., for permitting the adaption of various documents for this article.

Mr. Stephens is co-chairman of the committee to develop wheelchair standards for the 12th National Standards Conference in 1995. Dr. Hobson is president of RESNA. RESNA is the American National Standards Institute (ANSI)-designated U.S. standards developer and the designated U.S. representative to the International Standards Organization in the area of rehabilitation and assistive technology.

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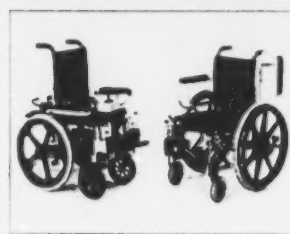


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The crossbrace exchange program makes wheelchairs a real savings as youngsters grow into adults and need seat widths and depths up to 20".

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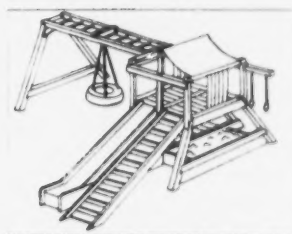


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TECHNOLOGY BULLETIN BOARD

WE RECENTLY INVITED ALLIANCE FOR TECHNOLOGY Access centers to submit success stories describing individuals or families who have incorporated technology into their lives. This is *Exceptional Parent's* second installment of these stories.

In many cases, specific products illustrate the wide variety of technology tools available and represent a few of the many products demonstrated and used at ATA centers.

ATA Scrapbook of Success

Self-esteem gets a boost

Technology doesn't have to be radical or specialized for a child to benefit greatly.

At TASK (Team of Advocates for Special Kids, the ATA center in Anaheim, Calif.), we have seen children with learning disabilities make great strides through access to computers and standard educational software.

Cecilia is a 12-year-old girl who attended our summer computer lab and, according to her mother, "got so good, I couldn't keep up with her." During the summer, Cecilia, who has learning disabilities, developed a real interest in computers.

Her mother found that Cecilia was able to grasp visual/spatial concepts on the computer that she otherwise didn't understand. She was also motivated to practice math, touch typing and writing.

In addition, Cecilia became familiar enough with the computer that other children would go directly to her with their questions, which was a tremendous boost to her self-esteem.

For Cecilia, the technology didn't have to be adapted to make it accessible — it only needed to be available.

Discovering the right tools

Garth is an adorable three-year-old boy whose physical and visual disabilities make it difficult for him to interact with his environment. Some people may have felt he wasn't

capable of interacting, but now that he has a computer with single-switch games, he is able to show everyone his abilities.

He visited the Computer Access Center (the ATA center in Santa Monica, Calif.) with his parents during a preschool recreation program for children with and without disabilities. At first, it was difficult to discern whether he was reacting to the cause-and-effect software he tried, but together we discovered the right tools. His current favorite is *Children's Switch Progressions*, newly released in an MS DOS version.



Garth shows everyone his abilities through single-switch computer games.

Taking control

Steven Lee is a 16-year-old student who had a brain stem stroke in May 1992. The speech/language pathologist at the hospital requested a consultation with TASC (Technology Assistance for Special Consumers, the ATA center in Huntsville, Ala.).

We first met Steven and his family late one Friday afternoon. Steven was using a respirator and could not talk or move his limbs, head or eyes.

TASC brought an environmental control unit that scans through eight lights, each corresponding to an electrical outlet in the room. All Steven needed to do was touch a switch with his chin to turn on a light, a fan, a television or any appliance plugged into those outlets.

During this visit Steven did touch the switch but it was unclear if

his movements were intentional. Steven tired quickly so we left the control unit with him and planned to return in a few days.

When we came back on Monday, Steven was lifting his head from the pillow and using the environmental control unit intentionally. He had even learned how to program the speed of the fan and the number of television channels by himself. Steven and his parents were thinking more positively about Steven's recovery.

Steven was discharged three weeks later and took the environmental control unit with him. Once he was situated at home, we brought over a Macintosh PowerBook with *Ke:nx* and *Co:Writer* installed. This allows Steven to select letters from the alphabet through scanning and single-switch selection and provides voice output and word prediction to reduce the keystrokes required.

Steven immediately saw the potential and without hesitation started to create sentences with hardly any instruction. One of his first sentences was, "Please don't take your computer home!"

TASC worked with the family to help them find funding for this equipment from local civic groups. Steven is now teaching himself how to use *MacDraw* and he is looking forward to returning to school when he is out of intensive rehabilitation.

Ke:nx and *Co:Writer* are available from Don Johnston Developmental Equipment, P.O. Box 639, 1000 N. Rand Rd., Bldg. 115, Wauconda, Ill. 60084, (800) 999-4660. *Children's Switch Progressions* is available from R.J. Cooper & Assoc., 24843 Del Prado #283, Dana Point, Calif. 92629, (714) 240-1912.

The Alliance for Technology Access (ATA) is a network of community-based technology resource centers dedicated to providing access to the assistive technologies and related services that enable people with disabilities to achieve productivity, independence and success according to their individual needs and interests. ATA centers serve people of all ages with disabilities of all kinds and have comprehensive, multifaceted programs that reflect their specific community needs, as well as local talents and resources.

For more information about the ATA and the center nearest you, call (800) 992-8111 or (510) 528-0747.

"Meetings are always unpleasant for us."

Family Stress from Parent-Professional Conferences

"I don't think my husband and I should go to conferences about our son, Bill."

Nancy Wilson, a tall, slender woman in her early thirties, smiled nervously when she spoke. "Maybe we shouldn't have even come here together either."

"Last week my husband Jack and I went to a review conference at the hospital's augmentative communication center where they are working with Bill on his communication skills. Bill was born with cerebral palsy and it's almost impossible for him to communicate or talk to people clearly. We were very lucky to have a good pediatrician who got us involved with the group at the hospital. They have worked with Bill since he was two. He's now nine years old."

"Several years ago he started using a computer that allows him to speak his words directly via one of those voice synthesizers. It's been like a miracle. We always thought he was intelligent because of how alert he was. And he seemed to respond to us and whatever we were saying, but we weren't always sure he understood us."

"We have been very pleased with Bill's progress. Since last year, when he was in third grade, Bill has been in a regular

classroom; the people at the hospital have been a big help to Bill's classroom teacher."

"So last week, we were having our conference with the team at the hospital along with the special education director and the classroom teacher. But no matter how much Jack and I plan in advance, these meetings are always unpleasant experiences for both of us. By the time we got home this time, we weren't speaking to each other. That lasted two or three days. Then I called our pediatrician. He suggested we

contact you about our problem."

"Somehow no matter how much we promise not to, we always start to disagree in front of the people at our conferences. Jack thinks we should discuss things in advance. But we never really do. He asks me what I think but we don't actually discuss anything. The first time I hear what he thinks is usually at these meetings."

"I've been very pleased with Bill's progress in school. I was interested in finding out what they all thought the next step was and how much further Bill could go in his current school program. I

was hoping he could move to the more advanced classes in the near future. At this point, Jack started to criticize me. In front of the others, he told me that I was always pushing Bill too much, and that I was unrealistic about what he could achieve. Jack said we were spending a lot of time and money and he felt it wasn't always helpful for Bill."

"No matter how much I told everybody about how well Bill is doing with his school work and his friendships, both at school and at home, Jack kept focusing on the things Bill can't do. If I said Bill was getting along with more friends, Jack would talk



Illustrations by Robin Courchesne

about an episode in which Bill wasn't able to share and his friend went home. If I talked about how Bill's been taking more responsibility for keeping track of his homework, Jack would say that if I wasn't after Bill all the time, nothing would get done. When I said I thought Bill was becoming more independent, Jack said that we would never know until we let him do something on his own. Then, Jack said I should let Bill make mistakes; if he fails, he fails. When we got home, we didn't talk.

"This is the way we tend to handle disagreements. Sooner or later, Jack will tell me what should be done. If I complain about it, he usually tells me that it's what I had wanted in the first place. But to me it seems like a decision that's made without me. I feel left out. It's very confusing. Sometimes, I feel discouraged when I listen to Jack and when I tell people how discouraged I am, then Jack will be very upbeat. It's almost as if we haven't been talking to each other.

"We also don't seem to have heard the same things when we come away from a conference. Anyway, this time I felt that the professionals agreed about how well Bill was doing. I heard them encourage me by telling me how much they were going to try to do with him in the next few months. It's bewildering. There are times when I wonder whether Jack and I can work together at all. Then there are other times when I'm not sure if it's all worth it. Maybe we'd better find some other way. Lately I have begun to worry about our marriage — we vacillate between silence and outbursts — and we don't seem to enjoy anything anymore, including our friends."

"It's just as bewildering to me as it is to Nancy." Jack Wilson, a 35-year-old with a grim face, spoke quickly. "If you ask me, ordinarily I would say we have done a good job working together.

"We each do different things

well. I'm better organized than Nancy is, and I tend to keep better track of Bill's program. While I keep track of the various visits, Nancy is much better at dealing with people than I am. I tend to be abrupt and very direct, and not always as pleasant as I should be. Even when I intend to do better, somehow when I get into these meetings, that's the way I begin to behave.

"The other thing that Nancy talked about, which I think I understand a little bit, is that when one of us is up, the other one is down.



"There are times when I wonder if we can work together at all."

Right now I seem to be a little bit more discouraged. I've been looking back at the last nine years and it seems like we've done nothing but devote our time to Bill. So, part of me is happy about how well he's done, but the rest of me is wondering what we've done to ourselves.

"But I see us as a team that balances each other. We have different ways of doing things. That's what I liked about Nancy when we first got married. She is much more open about everything she's thinking. Although I can be direct, I'm much more likely to plan and turn it all over in my head a couple of times first. I know that's confusing for me sometimes because Nancy would have

made an argument and I'll listen to her and what she thinks we should do. Then a week later, I'll come back and tell her I agree with her. But that never makes her happy — she says we don't discuss things between conferences. I used to think we worked together. But lately, she goes out of her way to criticize me in front of our friends. She says she's sensitive, but what about me? I used to only worry about the conferences; but now, I'm worried about our marriage, too."

Summary and Conclusions

Mr. and Mrs. Wilson came in shortly after a school conference for their nine-year-old son Bill, who has cerebral palsy. The conference followed the painful course that all conferences about their son had followed in the past several years. Mr. Wilson believed he spent a lot of time thinking about his life and getting his wife's opinion before the meetings. At the last meeting, he felt Mrs. Wilson had betrayed him by criticizing whatever he said. He indicated that no matter what position he took, she would defend the opposite view — if he was optimistic about Bill's progress, she would be negative and vice versa. Lately, Mrs. Wilson had also begun to criticize Mr. Wilson in front of friends.

Mrs. Wilson argued that her husband would ask her what she thought about their son's progress, but then there would be no discussion of his opinion until she heard him talk at a conference. Mrs. Wilson felt that conferences were the first, and sometimes only, chance to discuss Bill. After any problem, Mr. Wilson would not talk to Mrs. Wilson for several days. At first, she was very hurt by how angry he seemed, but in the past year she preferred the silence. Mr. Wilson was surprised by his wife's fear of his anger. He claimed he avoided her because he was afraid of further criticism.

Mr. and Mrs. Wilson agreed that they each "heard" very different

continued on page 82

continued from page 81

things at the same meeting and often, since they did not talk to each other afterwards, they would not know this until several months later. In the meantime, they would both think they were each acting in the best interest on their son. They were both concerned by how little time they had for themselves and how in the years since Bill's birth, they had slowly drifted away from some of their friends. After the last conference, they wondered what was wrong with them and whether their marriage had been permanently damaged.

Parents often find clinical or educational conferences with professionals about their children difficult because they tend to view a report on their child's progress as a "report card" of their success as parents. They often underestimate the importance of their own observations and overestimate the value of the many observations and judgments made by others over the course of their child's life. Unfortunately, there is often little in the preparation of professionals about how to discuss children with parents. Good parent-professional conferences are based on mutual respect. Because parents and professionals see the child under different circumstances, they have different observations and judgments. The purpose of a meeting is to enrich everyone's understanding. Only when each participant's input is respected and appreciated will the most comprehensive understanding of the child be developed. This mutual sharing can only enhance any plans that are being formed.

This collaborative process is essential when a child is having difficulty dealing with the challenges of growing up due to emotional, intellectual or physical reasons. It was no surprise that the Wilsons found conferences difficult. Parents can often feel that they are failures as parents and tend to blame themselves if a child struggles, even if the child's

problem has little to do with parenting. Sometimes professionals convey these negative, blaming attitudes. But even when professionals convey positive ideas and reassurance, parents may still judge themselves harshly.

All parents must modify the expectations they had for a child before he or she was born on the basis of a child's abilities and interests. When parents dream of a child as a great athlete, they must gradually adjust their expectations for a child



"She goes out of her way to criticize me in front of our friends."

with modest athletic abilities. These modifications take place over a period of time and are relatively easy when parents are confident that the child will grow up to be a successful, independent adult.

For parents of children with disabilities, the process of modifying expectations is much more complicated. Usually, there is little in parents' own lives that can prepare them. Because their child's future life as an adult is often unclear, parents can feel helpless about their "limited" ability to help their children. Every meeting about their children can make them feel worse. Each parent may have a different way of handling these difficult experiences. Then, while preoccupied with his or

her own concerns for a time, one may not be aware of the spouse's concerns. Like Mr. and Mrs. Wilson, each may increasingly believe that their spouse is unsupportive and lacks understanding. Conferences can also be reminders of how difficult parenting can be. Unfortunately, at a time when parents need to be able to support one another, they often withdraw and/or fight.

Meeting with friends can create similar problems. Friends often express friendly rivalry in comparing the progress of their children. Parents of children with disabilities can find such discussions very painful and erroneously attribute criticism and rejection to friends.

Mr. and Mrs. Wilson were relieved to learn that their problems were not unusual. They realized how committed they both were to their son and how hard they worked together. They began a program of couples therapy to learn how to listen and talk to each other. They quickly found that it was easy to misinterpret each other's behavior and how much more constructive, though possibly painful, it was to ask and tell each other what they each thought.

In the process, they discovered that their friends actually admired their work with Bill, but had stayed silent because they did not know how to talk with the Wilsons either. Mr. and Mrs. Wilson increased their involvement with their friends and improved their own relationship as well as their ability to discuss everyday events.

— M.J.S. —

This case has been selected from private practice and consultation files. The names and circumstances have been changed to preserve confidentiality.



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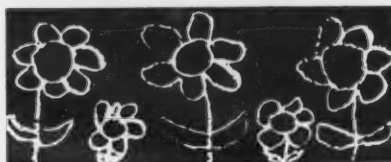


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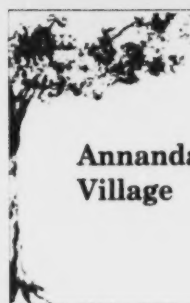
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SCHOOLS, CAMPS & RESIDENCES GUIDE



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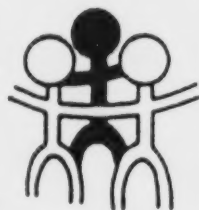
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FAMILY SUPPORT

continued from page 11

center. I am looking for ways to make the center fun for the teens with disabilities in our area. Any ideas would be welcome. I have thought a craft night, D.J. dance night and once-a-month trips to area attractions could be implemented.

Also, I would enjoy hearing from other single moms raising a child or children with disabilities.

S.A.M.
Florida

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B.J.M.
Nevada

Parents Search is an opportunity for our subscribers to get information from parents about their practical experience in handling the everyday problems of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Anyone who wishes to submit or reply to a letter in *Parents Search* or *Respond* should write to:

Exceptional Parent
1170 Commonwealth Ave., 3rd Floor
Boston, Mass. 02134-4646.

Please indicate whether it is a **search** or **response** letter and in which issue the original letter was printed when addressing a reply. All responses will be forwarded and may be published in our *Parents Respond* column.

For technical information about a disability, we encourage you to contact NORD (P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518) or refer to *The Annual Directory of National Organizations, 1992-93*, in the September 1992 issue of *Exceptional Parent* (available from the above address for \$6 including postage and handling).

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Harvard Medical School*

*Author of Doctor and Child, On Becoming A Family,
What Every Baby Knows, Infants and Mothers,
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SCHOOLS, CAMPS & RESIDENCES GUIDE



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Tips Editor

Exceptional Parent

**1170 Commonwealth Ave.
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Problem: When I had to let my then three-year-old go so he could get some early intervention, I was a nervous wreck. What if he needed me? What if they didn't understand him?

But I let him go. And whenever I was needed and they called, I was home. (I seldom went anywhere while he was at school.)

But after my daughter was born, her needs became as important as his and sometimes I had to go out. One day there was an accident. My son had fallen against a water bubbler and knocked out his two front teeth. I was not home to answer the school's phone call, and his father could not be reached at work.

My son sat there for one hour, controlling his sobs, his pain and his confusion before his father raced to his aid. The "what if" had happened and we were not available. How could we ensure that "what if" never happened again?

Solution: The very next day I went out and got my own beeper — me, somebody's mother. Not employed or dispatched

by a big company, just me, my very own peace-of-mind-clipped-on-the-belt beeper.

I paid 15 dollars for such a luxury — the cost of makeup I never used, clothes I never needed and bingo I will never play. The freedom I have, the ground I can cover and the places I can go. "What if" can find me anytime, anyplace, anywhere.

This freedom has allowed me to be an advocate for all children. I'm very active in parent organizations which always meet in school at night when the offices are



closed. How do they get me if they need me? BEEP-BEEP!

When advocacy takes me to the state capitol to lobby important legislation, I've been known to brown-bag it in a senator's outer office while waiting. "What if?" BEEP-BEEP!

When I'm home working on the property, planting a garden or napping in the sun. "What if?" BEEP-BEEP!

I remember the day I was at the high school in a conference with the principal. One mile away, the middle school's heavy duty chemical cleaning concentrate was spilled. My middle child had a cold and her asthma overwhelmed her. She went right to the nurse's office and the nurse beeped me.

In the same time it would have taken to call an ambulance, I was there. We all know that the nurse as well as my child would rather have the mother there. Within 15 minutes she was sitting on the table in her doctor's office recovering from the emergency adrenalin shot necessary to restore her breathing. Her "what if" had come and gone. The beeper had me there with her and it paid for itself that day.

Today my son is in high school. He leaves the house at 7:30 a.m. and I'm on my way to a meeting 10 miles away. At 9 a.m., a malfunctioning boiler in his school causes acrid black smoke to fill all the corridors. The student body is dismissed from the building. At 9:05 a.m. my beeper goes off. "Your son was sent home — fire in the building," says the recording. Yipes!

As I leave the meeting and drive down the highway,



And it did.

He was home alone. He knew the call had been made to the beeper and I was on my way home. He went to the phone and called my mother.

"Grandmother, I am home alone. Please come and get me." Because my mother lives right down

the street, she got there five minutes before me. They left a note and went off happily for an early-morning adventure. The beeper and I collapsed in a chair, grateful our system had worked, and our back-up system worked even faster. It is comforting to know my mom is there for us and the beeper backs her up, too.

Not only has the beeper serviced the needs of our special needs son, it has given us peace of mind. The service has met the needs of the entire family once, twice and more.

I would urge everyone to look into this luxury. Even when it doesn't go off for days and days, I love it!

*Veronica Andrews
Massachusetts*

WE NEED YOUR TIPS!

If you have an idea or tip that has made life with your child with a disability a little easier, why not share it with our readers? You'll receive \$5 for each published tip.

Send tips and any necessary photos or diagrams to:

**Tips Editor
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It's a Knockout!

by Alice Wershing

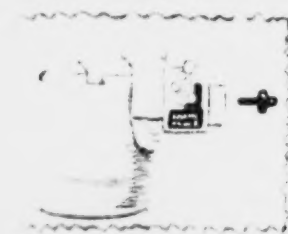
Strategy, skill and fun are all part of a game that lets kids be safely destructive. They first build a neatly balanced wall with a bunch of neon plastic bricks. Then they knock out selected bricks with a battery-operated rammer hammer, being careful not to knock down the wall. Players place the knocked out bricks on top of the wall while trying not to displace the special Knockout brick.

Milton Bradley's *Knock-Out*[™] includes plastic bricks that require assembly and a cardboard guide to help players build the wall by matching the brick shapes. The bricks can be matched to the guide while it's lying on a flat surface. The wall can then be raised by holding the blocks to the guide while lifting. The guide can also be leaned vertically against the box while players stack the bricks against it. To help players who may have trouble building the wall by matching the blocks' shapes to the guide, a color-coded grid can be created to stack the blocks by color instead. Once the bricks are in place, the Knockout brick is placed on the top row.

A roll of the die selects the color of the block to be removed. Pointing to colored cards or saying, "I'm going to knock out a blue block," might be easier methods than rolling the die for each turn. The player positions the rammer hammer in front of the block and tries to remove it. As each block is successfully removed, it is stacked next to or above the Knockout block for the next player's turn. Stacking the new blocks may be done by a partner if assistance is needed. Play continues until the wall is knocked down or until all the players have been "knocked out" of the game.

The rammer hammer can be stabilized to sit level on a table by adding a block of wood underneath the handle. The block of wood can also provide a larger surface for grasping the hammer. Attach the block by bending a piece of copper stripping over the top of the handle

and nailing it into the wood. The copper must be bent so there is a tight fit around the hammer. The activation



Elastic strips stretched across the top of a can will allow the hammer to reach blocks at various heights.

button on the rammer hammer is easily adapted by adding a wooden knob. Both of these modifications may be necessary for some youngsters to use the hammer successfully. They can then hold the hammer by its base while hitting the larger button.

As the wall grows taller, the hammer must be positioned higher to reach selected blocks. Place the hammer on blocks of differing heights to raise it. Another option is to cut an indentation out of a large can or sturdy cardboard mailing tube and stretch elastic strips across the top to create a flexible web on which the hammer can sit. Make sure the hammer can reach blocks at various heights by testing the position of the strips while pushing down on the hammer. Use a hot glue gun to attach the strips to the can or tube. The player can then push down on the hammer to reach lower blocks, while having it return to reach higher levels. If a can is used, pad the cut edges to ensure the safety of the players when using this adaptation. If the can needs to be stabilized for some players, secure it to a wider base.

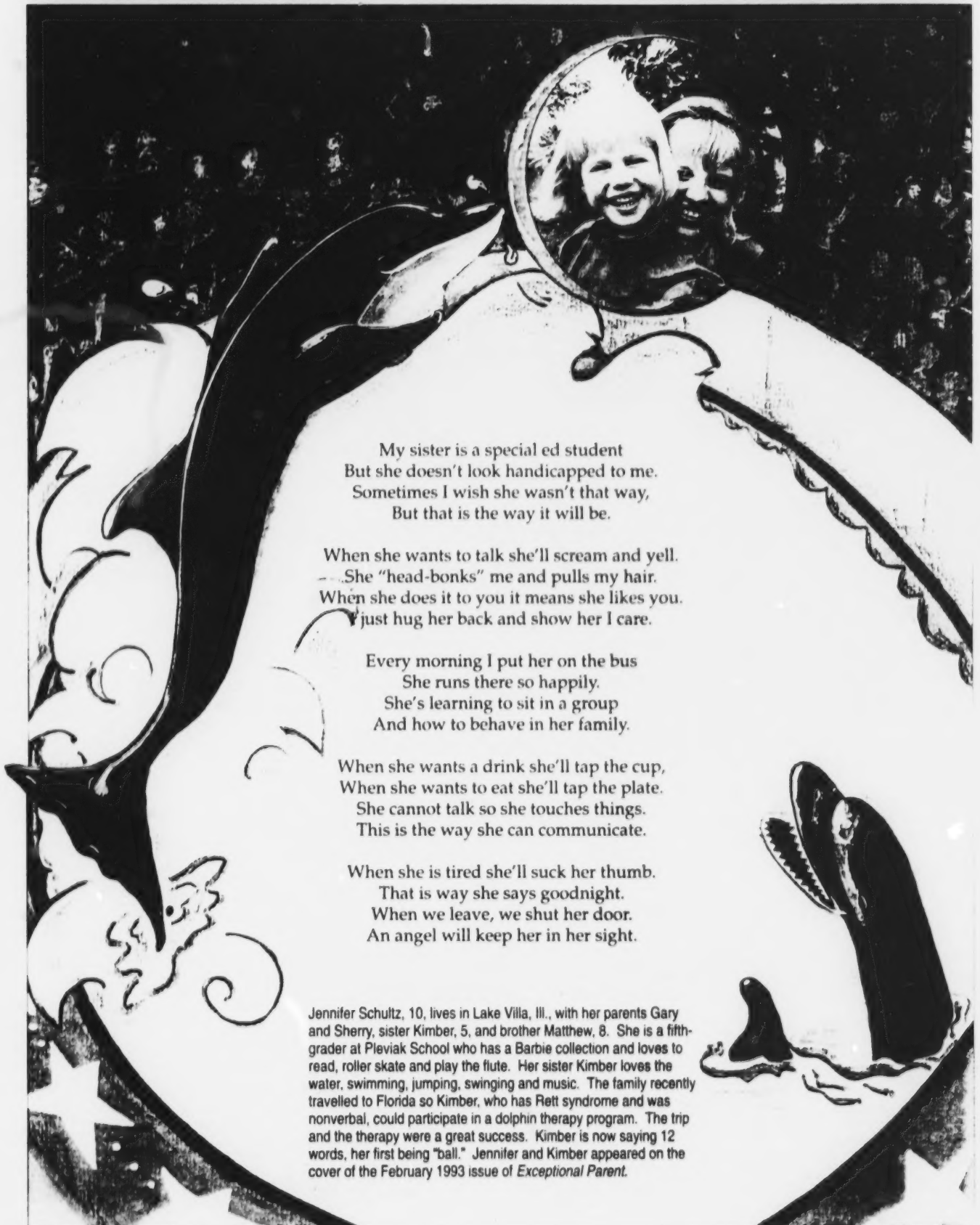
Have a blast!

Knock-Out[™] is available from Toys R Us. The author wishes to thank Jennifer Lemmons and Helen Miller for their assistance during the development of this article.

Alice Wershing is the Computer Resource Specialist and Toy Program Coordinator at the Disabled Children's Computer Group (DCCG): Technology Resources for People with Disabilities, 2547 Eighth Street #12A, Berkeley, Calif. 94710, (510) 841-DCCG.



Illustration by Kathleen Johnson Cox



My sister is a special ed student
But she doesn't look handicapped to me.
Sometimes I wish she wasn't that way,
But that is the way it will be.

When she wants to talk she'll scream and yell.
She "head-bonks" me and pulls my hair.
When she does it to you it means she likes you.
I just hug her back and show her I care.

Every morning I put her on the bus
She runs there so happily.
She's learning to sit in a group
And how to behave in her family.

When she wants a drink she'll tap the cup,
When she wants to eat she'll tap the plate.
She cannot talk so she touches things.
This is the way she can communicate.

When she is tired she'll suck her thumb.
That is way she says goodnight.
When we leave, we shut her door.
An angel will keep her in her sight.

Jennifer Schultz, 10, lives in Lake Villa, Ill., with her parents Gary and Sherry, sister Kimber, 5, and brother Matthew, 8. She is a fifth-grader at Pleviak School who has a Barbie collection and loves to read, roller skate and play the flute. Her sister Kimber loves the water, swimming, jumping, swinging and music. The family recently travelled to Florida so Kimber, who has Rett syndrome and was nonverbal, could participate in a dolphin therapy program. The trip and the therapy were a great success. Kimber is now saying 12 words, her first being "ball." Jennifer and Kimber appeared on the cover of the February 1993 issue of *Exceptional Parent*.

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Annual Summer
Program Awards

Adventures in Camping
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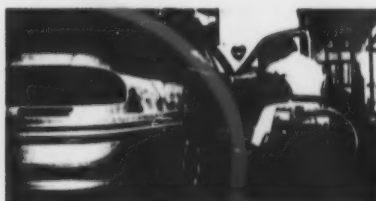
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Vicki Bertoldi
Parent

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221

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PARENTING YOUR CHILD WITH A DISABILITY



Cover: Leaf Lesson.
Michelle Coe, 4, explores
the great outdoors.
See story page 20.
Photo by Ellen Coe.

April/May 1993

Volume 23, Number 4

FEATURES

16 1992 Summer Program Awards

- ARC Summer Internships, N.C.
- Summer Adventure Series, Mo.
- Camp Pamunkey, Va.
- Summer Challenge Program, S.C.
- Easter Seal Camp, N.H.

20 Adventures in Camping by Ellen Coe

A single mother's quest to make camping possible for her daughter.

22 The Miracles of Brea by Chelle Howatt

The many difficulties and hidden rewards of a child with multiple disabilities.

24 Tough Choice by Carole Briggs Ayres

A family copes with placing their previously mainstreamed son in a residential school after he develops emotional and behavior problems.

28 Family Hall of Fame

Exceptional Parent inducts Siegfried Pueschel for his genetic and clinical research over the past 20 years.

30 Making Your Home Work — Ramps

36 EP's Guide to Summer Fun

Travel and recreation resources.

44 Special Book Excerpt

When Your Child Goes to School After an Injury

46 The Best Interests of the Child by Barry Romich



Page 22



Page 16

DEPARTMENTS

6 Family Support

Letters to the Editors, Parents Search, Parents Respond

14 Editorial

Being Realistic

38 Resource Section

A list of accessible Easter Seal Camps and specialized hospital-affiliated camps.

48 Technology Bulletin Board

ATA Scrapbook of Success.

50 What's Happening

Prosthetics and orthotics clearinghouse, PKU article published, new SSI rules, financial aid resource paper and more!

52 From the Bookshelf

Planning for the Future

57 Fun Stuff by Alice Wershing

Going bananas with Monkey Mania™.

68 Family Album by Nicole Riegel

My Best Friend



Page 20

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 9 times per year (Jan. Feb. Mar. Apr. June, July, Sept. Oct. Dec.) by Psy-Ed Corporation, 1170 Commonwealth Ave., 3rd floor, Boston, Mass. 02134-4646. All rights reserved. Copyright ©1993 by Psy-Ed Corporation. EXCEPTIONAL PARENT™ "Exceptional Parent" is a registered trademark of the Psy-Ed Corporation.
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Our six Summer Program Award winners present an exciting range of opportunities for children with disabilities and/or complicated medical conditions to enjoy the fun of the outdoors and make friends in integrated camp settings. We congratulate all the unsung heroes who have made the dreams of many children and parents become reality. For more ideas about travel and recreation, see *EP's Guide to Summer Fun* on page 36 and the list of accessible Easter Seal camps and specialized hospital-affiliated camps on pages 38 and 40.



Stanley D. Klein



Maxwell J. Schleifer

Summer Fun. Our cover girl, Michelle Coe, 4, studies nature on a camping trip with her mom, Ellen. Someone probably told Ellen Coe that camping with Michelle was "unrealistic." Yet, her wonderful, practical story, *Adventures in Camping*, explains how she did it.

Courage and Strength. In *The Miracles of Brea*, Chelle Howatt shares the challenges and joys of parenting and reminds us of the courage and strength of parents. Similarly, in the *Family Hall of Fame*, we are pleased to share the words of Siegfried Pueschel, a parent as well as a distinguished physician and friend. It also takes great courage and strength for parents to decide that a child needs specialized help. In *Tough Choice*, Carol Briggs Ayres discusses the decision to enroll her son, who is mentally retarded and mentally ill, in a residential school program.

Harsh Realities. Although our editorial, *Being Realistic*, describes a wonderful story of creativity and commitment to individuals with disabilities, Barry Romich's *The Best Interests of the Child* reminds us that all is not well as he describes the harsh realities of illegalities faced by many parents seeking needed services in communities throughout the United States.

Dolphin Therapy Program. To find out more about the program mentioned in last issue's *Family Album*, contact Dr. David Nathanson, Dolphin/Child Program, 10737 SW 104th Street, Miami, FL 33176, (305) 378-8670.

School Mainstreaming Awards

Now is the time to think of nominations for our School Mainstreaming Awards which recognize outstanding programs at the preschool, elementary and high school levels. To nominate your child's school, send a 1,000-word essay along with a 200-word summary describing the program. Please include photos (both black and white and color are welcome). Nominations must reach us by July 16, 1993. Send materials to: EP Mainstreaming Awards, *Exceptional Parent*, 1170 Commonwealth Ave., Boston, MA 02134-4646.

INDEX TO SPECIAL ADVERTISING SECTIONS

SECTION	PAGE #'S	SECTION	PAGE #'S
Home Access Buyers' Guide	32	Product Showcase	47
Van Conversion Dealers Guide	37	Media Buyers' Guide	53
Marketplace	43	Schools, Camps & Res. Guide	54, 56, 58

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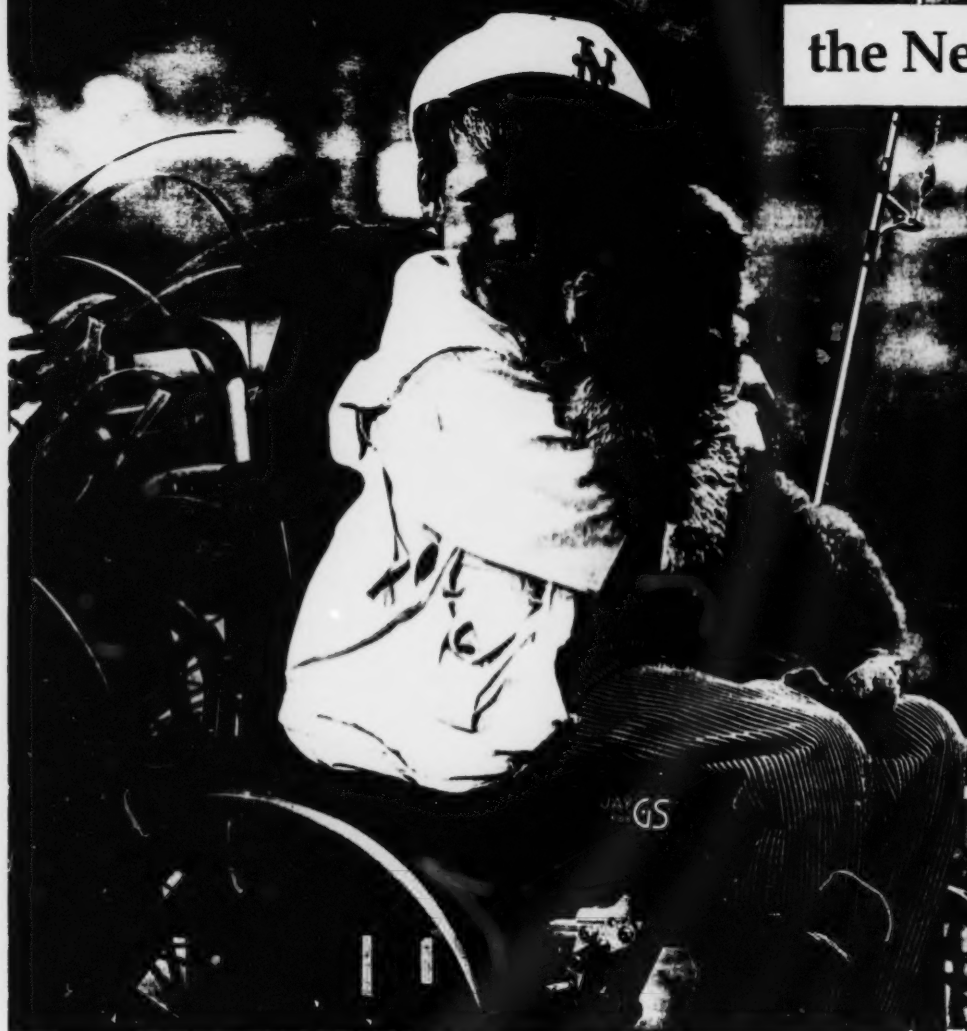
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Letters to the Editors

Profound Truths Receives Mixed Reactions

As a mother of a 10-year-old daughter with cerebral palsy, I was heartsick when I read the article *Profound Truths* (February 1993). Although my daughter has not shown signs of profound mental retardation, third-grade work is becoming harder for her. I wonder if Mrs. Fagley thinks that we should start looking for a "home" right away. My daughter uses a wheelchair. She is non-ambulatory and nonverbal. We must feed her, dress her, bathe her, etc. At least Evan can get around in a walker, point to what he wants and feed himself.

I have made many friends during the past years who have children with mental retardation and, like us, did not take the doctors' and experts' advice and institutionalize them. Everyone is coping very well, thank you. We aren't martyrs. We play the hand we were dealt.

I hope Mrs. Fagley read the article in the same issue titled *On the Ice* by Mary Greenlaw — that will bring her back to reality.

M.C.
Alabama

Editors' Note: *Exceptional Parent* also received many letters in support of Kathleen Fagley's article. Please see *Tough Choice* on page 24 for another family's perspective.

Parents Should Have the Right to Choose

It is Wednesday, so Andy is delivering messages around school. Yesterday, he went shopping in a local grocery store. Vocational training on Thursday will include

microfilming documents and sorting mail. Sounds good, doesn't it? Andy's dad and I think so. Unfortunately, his days in this wonderful program may be numbered. Although Andy is learning skills necessary for his success as an adult, the school where he has grown so much may no longer be a choice for him.

No one will admit to making the decision to force Andy and his classmates out of their school, but many school officials are using the right to the least restrictive environment as an excuse to manipulate children and their parents.

Including children with disabilities in all aspects of life is an admirable goal. However, inclusion should not be used as a means by which choices are taken away. By using "mandated" mainstreaming or integration as a rationale, school administrators are taking away any choice that we, as Andy's parents, now have.

No matter how school officials manipulate children, they can fall back on the excuse that the parents could have fought for services for their children. What parents have the financial or emotional resources to fight year after year for opportunities for their children?

So now we wait to see what school officials plan to try this year. Andy's dad and I talk about what we will do if integration is forced and Andy can no longer attend his wonderful school. Should we move? Can we find and afford a private school?

I wonder if this was really the intent of the law. I cannot believe that anyone meant for parents to have no say in their child's education.

C.D.
Virginia

Autism and Sensory Disorders Network Formed

Our family has long been interested in networking with others involved with people who have autism

and sensory disorders such as hearing and visual impairments. We therefore have established a computerized data bank of families, professionals and others interested in autism and sensory disorders.

Our motivation stems from working with our 18-year-old son, Craig, who is autistic and profoundly deaf (congenital).

Our objectives in this data bank project are to establish a network for communication, education, research and advocacy for those with autism and sensory disorders and encourage the development of centers to diagnose and evaluate individuals with these disorders. If a newsletter is of interest, please let us know.

D.B. & A.B.
Virginia

Editors' Note: For more information, contact Dolores and Alan Bartel, 7510 Oceanfront Ave., Virginia Beach, VA 23451.

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- BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, Mich.
- SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, N.Y.
- HERBERT J. GROSSMAN, M.D., C.S., Mott Children's Hospital, Pediatric Neurology, Univ. of Michigan Medical Center, Ann Arbor, Mich.
- GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, New York, N.Y.
- SUSAN M. KLEIN, Ph.D., Prof. of Special Ed., Indiana University, Bloomington, Director, Early Childhood Prog., Inst. for the Study of Developmental Disabilities, Bloomington, Ind.
- EDWIN W. MARTIN, Ph.D., President & CEO, National Center for Disability Services, Albertson, N.Y.
- JAMES MAY, M.A., M.Ed., Project Director of the National Father's Network, Bellevue, Wash.
- JEAN B. McDREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, Ill.
- EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, Pa.
- BETTY PENDER, M.S., Member, New York State Developmental Disabilities Planning Council, New York, N.Y.
- HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, Mass.
- SIEGFRIED H. PUEBCHER, M.D., Ph.D., M.P.H., Dir., Child Dev. Ctr., Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, R.I.
- JEROME ROSNER, D.D., Professor of Pediatric Optometry, University of Houston, Houston, Texas.
- HIRSHY ROUSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, N.Y.
- BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, R.I.
- HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, Mass.
- CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, Utah.
- HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, Mass.
- IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, Mass.

We welcome all contributions to *Letters to the Editors*. Please send your questions, ideas and responses to:

Letters to the Editors

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Fortunately, things took a turn for the better when Judy Henderson and Peggy Barker of Packard Children's Hospital at Stanford recommended the DynaVox.

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"I assumed it would be hard to learn," says Vickie, "but I let her play with it for a day, and *Courtney* taught *me* how to use it."

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"This machine has totally changed her life," says Vickie. "It's made her independent. It's the next best thing to having Courtney speak for herself."

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Parents Search

Colon Interposition and Vomiting

Our five-year-old son was born with a birth defect known as tracheoesophageal fistula (no esophagus). He has had numerous surgeries to repair this as well as a webbed larynx. At 18 months of age, he had colon interposition surgery to make an esophagus.

Since the surgery, anything he eats or drinks comes up when he falls asleep. He is not allowed to eat or drink two to three hours before bedtime, but this does not control the vomiting. We have tried just about everything. His doctors feel that any more surgery might only worsen his condition.

We would like to talk to other parents with children who have had colon interposition.

C.H. & W.H.
Oklahoma

Trachs and Facilitating Breathing During Sleep

My six-year-old son, Mark, had a tracheostomy placed when he was six weeks old due to a floppy windpipe (tracheomalacia). At age two, that trach was removed because his windpipe looked normal when observed by bronchoscopy.

However, four months later the tracheostomy had to be replaced because he was not oxygenating well during sleep due to upper-airway obstruction.

Currently, Mark's trach is plugged in during the day, which allows him to breathe through the upper airway, then the trach is unplugged at night so he can breathe comfortably. Mark was born with multiple congenital defects with severe delays and no diagnosis of a syndrome.

I would love to hear from parents or professionals who know of a child who is trached primarily to facilitate breathing when asleep. I would also like to find out if there is

any other way to help him breathe during sleep without the tracheostomy. The medical staff on Mark's case have used CPAP (constant positive airway pressure) on adults with upper-airway obstruction but have no experience using this on children.

B.O.
Wisconsin

Multiple Diagnoses and Questions About the Future

I am writing about my three-year-old daughter, Brittnie, who has a number of diagnoses. The doctors are unable to tell me what to expect for her future. She has a thin corpus callosum, cerebellar atresia, ataxia and is also developmentally delayed. I recently found out that my other daughter, 22-month-old Ashley, also has a thin corpus callosum and is developmentally delayed.

My girls will soon be genetically tested. I was hoping to correspond with a parent, particularly a single parent, of a child with the same disabilities. I would like to find out what I can expect from these conditions in Brittnie's future.

The doctors say they cannot tell me because she is so young, but anyone who has already gone through this could possibly help me. Any information would be greatly appreciated.

S.P.
Michigan

Glycogen Storage Disease

Our 20-month-old son, Trevor Michael, was born with glycogen storage disease type 1B. It takes our whole family to take care of him. He has two sisters, 11 and 13, and one brother, age two-and-a-half.

Trevor has a G-tube for night feedings and is on cornstarch feeding during the day. We have difficulty knowing what diet plan to follow and then getting him to eat. Trevor also has a low white blood cell count and hypoglycemia, so we test his

F.Y.I.

An Overview of Attention Deficit Disorder (ADD)

Children with Attention Deficit Disorder (ADD) are characterized by symptoms of inattention, impulsivity and sometimes hyperactivity which have an onset before age seven and persist for at least six months. These children comprise approximately 3 to 5 percent of the school-age population, with boys significantly outnumbering girls. A child with ADD will exhibit some of the following symptoms:

- Fidgets with hands or feet; squirms in seat.
- Is easily distracted by extraneous stimuli.
- Has difficulty waiting for turns in games or group situations.
- Has difficulty following through on instructions from others.
- Shifts from one incomplete activity to another.
- Has difficulty playing quietly.
- Interrupts or intrudes on others, e.g. butts into other children's games.
- Does not seem to listen to what is being said to him or her.

To date, no one knows for certain what causes ADD. Evidence suggests, however, that a chemical imbalance or deficiency in certain neurotransmitters may be the root of the problem. Recent research done at the National Institute of Mental Health has supported this. Evidence also suggests that ADD frequently results from a hereditary predisposition.

A multi-model approach to assessment, diagnosis and treatment is important for a successful outcome. Behavior modification, counseling, appropriate education management and medical intervention when indicated are key components to the multi-model approach.

It is no longer believed that ADD is outgrown, and approximately 80 percent of young children diagnosed with ADD continue to experience symptoms in adolescence. Most experts agree, however, that the risk for the poor outcome of ADD children and adolescents can be reduced through early identification and treatment. By recognizing the disorder early and taking the appropriate steps to assist the child with ADD and his or her family, many of the negatives commonly experienced by the child can be avoided or minimized to protect self-esteem and avoid a chronic pattern of frustration, discouragement and failure.

Resource: *Children With Attention Deficit Disorders — ADD Fact Sheet* was produced by Children with Attention Deficit Disorders (C.H.A.D.D.).

This excerpt was reprinted with permission from C.H.A.D.D., 499 NW 70th Avenue, Suite 308, Plantation, Fla. 33317.

blood daily.

We know of the G.S.D. Association but would like to hear from parents who have a 1B child. We live in a very rural town (population 500) and many doctors do not know what to do with our son.

D.N. & E.N.
California

Cerebral Palsy and Lack of Communication

My seven-year-old son, Chester, has cerebral palsy and pale optic nerves which cause limited vision. He was born two months premature and weighed two pounds. He can't walk or sit without support, and he has a lot of extension which makes even the easiest tasks difficult. He needs assistance with everything.

Chester has very limited speech and answers most questions with yes or no. He is a very smart child, but his lack of communication can be frustrating for him. He attends a

regular kindergarten where he is a very popular student. He loves school.

I would like to hear from parents who are in similar situations. I am also looking into toilet training this summer and if anyone has any helpful hints, I would be very grateful to hear them. Finally, if anyone can give us some input on communication devices, that would be helpful as well.

K.L.
Maine

Microcephaly

My one-year-old daughter, Jordan, has microcephaly, questionable vision, a dislocated hip and deformities of both feet. Her muscle tone is low; however physical therapy has helped her greatly. She is also developmentally delayed.

I would be interested in hearing from other families whose children have microcephaly with similar

problems. I would like to know what testing was done and what progress their children have made.

A.A.
New York

My two-year-old son, Taylor, has microcephaly. His eyes are also misaligned (strabismus). Taylor attempts to pull up into a sitting position and crawl. His fine motor skills are very delayed. He is happy and very social. He has shown progress, although it has been extremely slow.

I would like to correspond with another mother who has a child with microcephaly (preferably an older one than mine).

K.H.
Tennessee

Cerebral Palsy/Irritability

Our daughter Amanda suffered cardiac arrest shortly after birth. Because of this she has cerebral palsy and must be fed through a G-tube.

continued on page 10

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continued from page 9

The problem we have is with her irritability — she screams constantly.

Her neurologist has taken her off all medication and says we just have to ride through this. After two years, I'm at my wit's end. We cannot go anywhere or do anything because of her irritability. I would greatly appreciate hearing from any families who have been through this and learning how they resolved the situation.

B.A.
California

Brain Injury at Birth

I am a mother in search of some hope, wisdom and knowledge. My eight-month-old son sustained a brain injury at birth and was given no prognosis or diagnosis. He has a strong little body and tries hard, but I'm just not seeing him do things like I had hoped. I know it's early, but the stress and fear have led me down a path of despair.

Anyone who can give me some hope and words of wisdom, please write. I need all the help I can get. My faith in medical professionals is gone and some days I feel that my life is not of much value anymore.

J.L.
Nebraska

Cytomegalovirus — Possibly Related to Drug Addiction?

My adopted son was born with cytomegalovirus (CMV), complicated by an addiction to cocaine. He is profoundly deaf and has pervasive developmental disorder with autistic tendencies.

Educational programs for children with multiple disabilities, like my son, are almost nonexistent. After waiting for funding to come through our school district and the state educational system, a private school for the deaf in western New York made placement available for him. Mainstreaming was not a

consideration. Being taught on a one-on-one basis is of vital importance to children like my son.

I've never heard of special interest groups or any articles on the subject of CMV or the combination of CMV and children born with a drug addiction. At the time of my son's birth, two other children were born with CMV and drug addiction at the same hospital. Is there a correlation between CMV and drug addiction? Are there support groups for families of these children with multiple disabilities?

Professional personnel in my area seem reluctant to discuss CMV and drug addiction. Our developmental pediatrician is more concerned about what we expect to gain from a visit to his office than giving detailed information on the issue. His only explanation of CMV is retardation.

S.W.M.
New York

Parenting Two Children with Disabilities

We have a three-year-old daughter who is undiagnosed. She has had every test that we know of — an MRI, muscle biopsy, evoked response lab test and more blood tests than I can count. So far everything has come back normal.

She is very small for her age and is hypotonic. She does not walk or crawl, though she sits with good balance. She also has speech delays. The doctors have recently said that she has a rare metabolic disorder but they cannot give us any more information. It is very frustrating not knowing and wishing we could do something for her.

We also have a six-year-old son with cerebral palsy. He was born premature at 28 weeks. He has spastic quadriplegia but has improved tremendously since rhizotomy surgery more than a year ago. It was the best decision we ever made for him. He is very intelligent and is starting to be mainstreamed in kindergarten.

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We know why our son has disabilities, but the lack of a reason for our daughter is very frustrating. At times it is really tough handling two children with disabilities. We haven't met many parents in this situation and we are eager to hear from any parents who have two children with disabilities.

M.S.
Maryland

Undiagnosed/Possible Arthrogryposis

My 17-month-old daughter, Gretchen, is unofficially undiagnosed although everyone agrees she has some type of arthrogryposis.

Gretchen is involved orthopedically with aggressive therapy (no surgery) and her left-sided problems are improving all the time. Gretchen's key problem is that she has no suck, swallow or gag reflex. She is fed via G-button and is bulb suctioned with every cough and sneeze to maintain a clear airway. She is not trached by choice.

She has high-arched grooved palate (not cleft) and low facial tone. Just in the last few months she has developed voluntary tongue movement, good babbling (not speech) and more oral/facial expressions.

Gretchen is a completely different child than the one born 17 months ago with a rather morbid prognosis. All of her reflexes have returned except the swallow/gag reflex. Based on her incredible development, we hope that this reflex will also return. She does receive oral therapy which has made a huge difference. Gretchen's cognitive and receptive language skills are advanced for her age.

If anyone can help us in this matter in any way, please contact us. Case studies, therapies, procedures, etc. are all welcome.

N.V.
California

Alpers Disease

I am searching for other parents whose child has or had Alpers

disease. Our daughter Bethany was diagnosed with it in late December and I would like to establish some contact with another parent or family who has gone through this.

S.G.
Missouri

Carbohydrate Deficient Glycoprotein Syndrome

I am looking for information on carbohydrate deficient glycoprotein syndrome (CDG) or possibly an

organization that is familiar with or willing to investigate CDG. My daughter and son were both diagnosed with CDG, however, it seems to be a "new" syndrome with little written about it.

I am also very interested in starting a CDG network/advocacy group. Networking brings parents with similar situations a feeling of unity and purpose. I know because for six years, my children were

continued on page 63

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Parents Respond

CHARGE Association/ Toilet Training

A response to J.P.T.'s Parents Search,
February 1993.

My daughter Amanda was about five years old when she was toilet trained. She has a different diagnosis than your son, but I noticed some similarities.

Amanda has cerebral palsy and

is quite delayed in her gross motor skills. She was almost three when she walked. Even today at age eight, she falls frequently and her gait is unsteady. Amanda has normal intelligence.

I feel it was Amanda's balance that caused problems with toilet training. To give you some idea, she would lose her balance on an

escalator, a doctor's scale, a swing, etc. The same thing happened when she would sit on a regular toilet. Even when I held her, she would get tense from not having her feet on the floor and lose her balance. She was using all of her muscles to hold herself on the toilet, so she could not relax enough to go to the bathroom.

What worked for her was a potty chair small enough so she could keep her feet on the floor and with high sides that she could hold onto for balance. Once we got her this chair, she was toilet trained fairly quickly.

It was quite a while before Amanda was able to use a regular toilet, but eventually she made that transition. I hope this can help you with your son.

B.C.
New Jersey

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Placement Decision

Response to G.H. & R.H.'s Parents Search,
November/ December 1992.

My seven-year-old daughter, Kimberly, does virtually nothing for herself. She weighs only 40 pounds, but I have difficulty lifting her on and off the bus, dressing, bathing, toileting her and anything else that requires physical strength.

I understand the dilemma you are going through since we have also decided to place Kimberly in a residential setting. This was not an easy decision, but we have two other children who have gotten the short end of the stick because of the time spent doing things for Kimberly.

She is on a waiting list, but we expect her to be placed soon. I'm sure that in the long run, this will be the best decision for our family and I hope the same for yours.

K.H.
North Carolina

Feeding Problems

A response to L.B.'s Parents Search,
November/December 1992.

Like you, we had a long period of time where we had to keep our child nourished by any means and

continued on page 66

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Being Realistic

For many years, parents of children with disabilities were told to be "realistic" about the abilities of their children. They were warned to be careful not to put their children into situations where they would be unable to succeed. And parents who disagreed with this advice and encouraged their children to take risks were considered parents with problems who were likely to damage their children. Even today, when parents look toward the future for their children, they are sometimes admonished by others to be "realistic." While well-intentioned professionals or friends and relatives may be trying to protect parents from the potential disappointment and pain of hopes unfulfilled, parents often feel their own understanding of their child and the future is being criticized.

Events at a recent meeting served as powerful reminders about how much "reality" has changed and how little any of us may really know about what the future holds. For many years, members of the American Association for the Advancement of Science (AAAS) have worked to encourage the participation of children and adults with disabilities in science and engineering. At a symposium at the annual AAAS meeting this year, a number of gifted young adults, who happen to have disabilities, and some college faculty members described efforts at major universities to facilitate the participation of students with disabilities in scientific and engineering programs. These individuals made it very clear that it is "realistic" for people with disabilities to be scientists and engineers and that to exclude a student with a disability from science- and/or engineering-related educational programs is discrimination. Nonetheless, AAAS leaders report that many children with disabilities continue to be discouraged from participating in high-school courses in biology, chemistry or physics — because it is unrealistic!

One presentation at the AAAS meeting dramatized this issue. As a result of an automobile accident, a graduate student at the Massachusetts Institute of Technology (MIT) in an advanced degree program in microbiology became a person with a physical disability. When this young man was ready to resume his graduate studies, questions were raised about his ability to complete his research mixing chemicals, preparing biological specimens or performing other scientific tasks in traditional ways because of his limited use of his hands and arms. However, under the guidance of dedicated faculty

members with a long-term interest in accessibility to scientific activities for people with disabilities, designing a research laboratory environment for the microbiology graduate student became the graduate project of a student in an industrial design program.

Some in the audience suggested that this could have been done more easily by employing another student (without a disability) to serve as a laboratory assistant to carry out the instructions in the microbiologist-to-be. While such an approach may well have been possible, using the individualized equipment created by the design student, the microbiologist was able to carry out his laboratory work on his own. When a member of the audience questioned whether doing the laboratory work independently was worth all the effort, another member of the audience — a well-known inventor who happens to be disabled and whose speech can be difficult for some to understand — reminded everyone of the importance of a scientist's active participation in his or her experimentation to the scientific process of understanding and discovery.

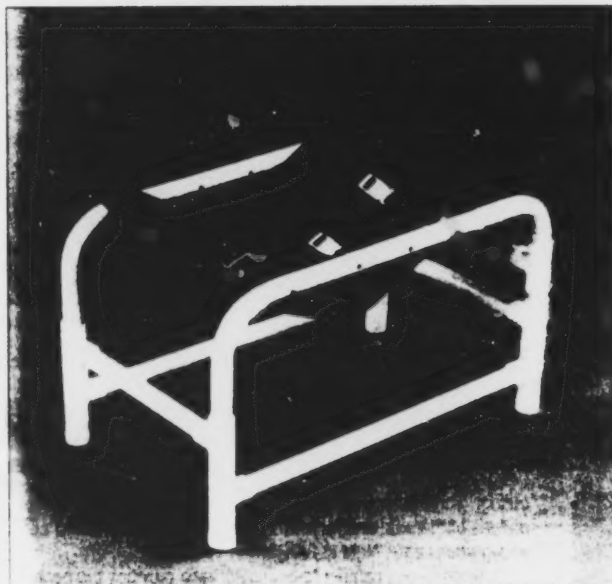
This example of actual participation in the process of scientific discovery can be applied to many fields of endeavor and to many aspects of day-to-day human experience. Learning via participation is familiar to everyone. Everyone knows that to master the challenges of day-to-day social interaction as well as to master the complexities of scientific fields — or music or art or medicine or sports or drama or carpentry or cooking — requires active participation and practice.

In recent years, we have reported many examples of how modern technology can assist a child or adult to maximize his or her potential. However, the most powerful changes have been in attitudes — and many more people believe we have just begun to see the potential for individuals with disabilities.

When children or adults with disabilities or their loved ones suggest something that may appear too unrealistic, let us all consider the potential for reality to change via new attitudes, ever-increasing accessibility, wondrous technology and, most of all, an openness to listen and a readiness to try.

— S.D.K. & M.J.S. —

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outing. The Easter Seal camp is coeducational and designed to provide both social and recreational experiences for children and young adults ages eight to 24.

A three-to-one camper-to-counselor ratio provides the necessary support campers may need to participate in activities. A camp director supervises counselors and manages the overall day-to-day operations of the camp. And, the Boy Scouts provide the programmatic staff for activities such as swimming, crafts, medical support, kitchen, etc.



Summer Adventure Series

St. Louis, Missouri

Now in its third year, STREAM's (the St. Louis Regional Experiential Movement) Summer Adventure Series is an inclusive camp for children ages six to 12.

Campers attend a one-week session in county parks throughout St. Louis and participate in activities adapted to the age and abilities of each child.

Campers are led by a mix of teachers and college students.

There are two theme programs:

On-the-Air KIDS Radio, which allows campers to spin records, report news and write and air commercials and skits;



and *Treasure Island*, where campers "walk the plank," hunt for buried treasure and escape the ghost of Long John Silver. Interpreters are provided for those who need them.

Community support is strong. Both programs are supported by county tax revenue, but donations of various art supplies by local businesses make crafts possible. The Department of Recreation waives park fees.

Parents are encouraged to attend on Fridays and are treated to puppet shows, stories and treasure hunts.

ARC Summer Internship Program

Orange County, North Carolina

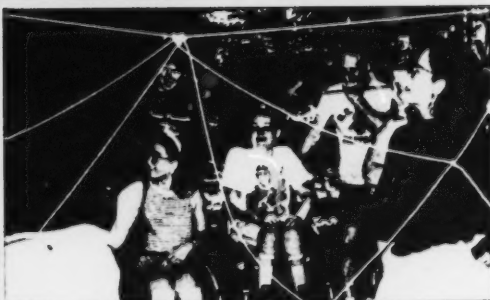
The Summer Internship Program of the Association for Retarded Citizens of Orange County, N.C., provides teens with developmental disabilities the opportunity to explore work and community living. The program places high-school students with moderate-to-severe mental retardation into community jobs for three-week rotations. Job sites from past summers included a hardware store, grocery store, physician's office and a newspaper.

Job coaches, hired and trained by the program director, learn the jobs, teach them to the interns and provide on-the-job supervision. The coaches then spend the afternoons with their interns, participating in community activities such as eating out, swimming, bowling and going to the mall.

The ARC/Orange County is looking to expand summer internships in a yearlong community skills and

vocational experiences for students with disabilities through the Transition Project. The Transition Project is funded by the ARC/Orange County and the Council on Developmental Disabilities.

"I know that lots of these kids will be able to work in the community," said one job coach. "So the burden of proof is now on the people who say they need a sheltered workshop."



Camp Pamunkey

New Kent, Virginia

Cumberland Hospital for Children and Adolescents is in its third year of hosting a special family camp called Camp Pamunkey for families from various parts of the United States. Sponsored by the Spina Bifida Association of America and the Agent Orange Class Assistance Project, the families spend a week living in two homelike lodges on the hospital's 1200-acre riverfront campus. During their week as "campers," the parents, children with spina bifida (ages 10 to 14) and their siblings participate in fun activities designed to be instructive and insightful as well. Side trips to nearby Jamestown and Williamsburg provide exposure to American history and a way to share a vacation-like experience.

At Camp Pamunkey, the campers can swim in the hospital's outdoor pool, hear from therapists and other specialists, canoe, engage in a family art project and go through a "ROPES" course of obstacles and elements useful in team building and group therapy.

A camp nurse is also available to advise families about personal matters such as sexuality and bowel/bladder concerns.

"We just can't say enough about Camp Pamunkey," wrote the Dickey family. "The staff was caring and always helpful. We learned so much in all the seminars. [They] have given us much to think about and work toward."

Summer Challenge Program

Hilton Head Island, South Carolina

The Summer Challenge Program at the island Recreation Center on Hilton Head Island, S.C., is a 10-week inclusion camp that mixes children with and without disabilities. Campers ages five to 15 are divided into classes by grade, age and mental and physical capabilities. The adults who work in the program have experience working in special education or early childhood education.

Children of all races, ages and abilities in the camp learn to share, support and accept children who have special needs. The Challenge Program is the only one in South Carolina and one of only two camps in the Southeast that combines children with special needs and those without.

The purpose of the program is to enrich the summer for children with mental and physical disabilities while they continue to develop motor, social and cognitive skills. Campers participate in a variety of activities including arts and crafts, field trips, cookouts, tennis lessons, swimming and quiet and active games.

In addition to the regular camp activities, children in the Challenge Program receive educational instruction from a middle school teacher. Each child's teacher lists goals for the child to attain throughout the summer, while helping the child retain what he or she learned during the previous school year.

The local Parent-to-Parent Support Group helped begin the Summer Challenge Program and collected funds from local organizations to send financially needy children with disabilities to summer camp.

"Without this program, many children would sit home all summer with little involvement with other children," wrote two mothers. "These activities continue the learning skills that these children have worked so hard for during the regular school year."



CAMP CONTACTS & ADDRESSES

WINNING CAMPS

ARC Internship Program — Ellen Russell, Executive Dir., ARC of Orange County, P.O. Box 649, Carrboro, NC 27510, (919) 942-5119.

Camp Pamunkey — Art Walker, Cumberland Hospital for Children and Adolescents, P.O. Box 150, New Kent, VA 23124, (804) 966-2242.

Easter Seal Camp — Lisa Lambert, Easter Seal Society of N.H., 555 Auburn St., Manchester, NH 03103-4800, (603) 623-8863, Ext. 219.

Summer Adventure Series — Nancy Lacey, STREAM, 1315 Ann Ave., St. Louis, MO 63104, (314) 968-8264.

Summer Challenge Program — Frank Soule, Island Recreation Center, P.O. Box 22593, Hilton Head Island, SC 29925, (803) 681-7273.

The Hole in the Wall Gang Summer Camp — James Schaffer, The Hole in the Wall Gang Fund, Inc., 555 Long Wharf Dr., New Haven, CT 06511, (203) 772-0522. *(To be featured next issue.)*

CAMP COMMENDATIONS

Camp Echo Aquatic Camp — Don Allen, Camp Dir., P.O. Box 36, East Lempster, NH 03605, (603) 446-7819 or Vermont Handicapped Ski & Sports Assoc., P.O. Box 261, Brownsville, VT 05037, (802) 484-3525.

Cedar Haven Summer Program — James D. Aubert, Administrator, Cedar Haven Rehabilitation Agency, 5595 Hwy Z, West Bend, WI 53095, (414) 334-1486, (414) 276-4370 (Milwaukee).

Camp Fairlee Manor — Easter Seal Society of Del-Mar, 61 Corporate Circle, New Castle Corporate Commons, New Castle, DE 19720-2405, (302) 324-4444, (302) 324-4442 (TDD).

IEP+ Camp — Dr. Joan Bruno, Program Dir., Children's Specialized Hospital, 150 New Providence Rd., Mountainside, NJ 07092, (908) 233-3720, ext. 339.

Project MAC (Mainstreaming at Camp) — Iran Buckler, Coordinator, Recreation Services, Young Adult Institute, 320 West 13th Street, New York, NY 10014, (212) 645-1616.

Talking with Technology Camp — Tracy Kovach, The Children's Hospital, B030, 1056 East 19th Avenue, Denver, CO 80218, (303) 861-6800.

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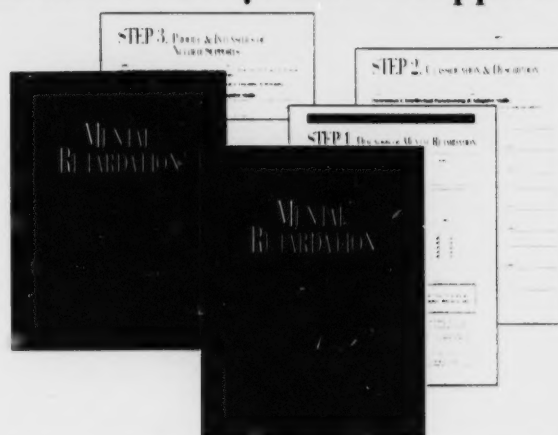
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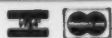
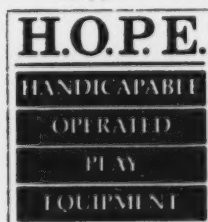
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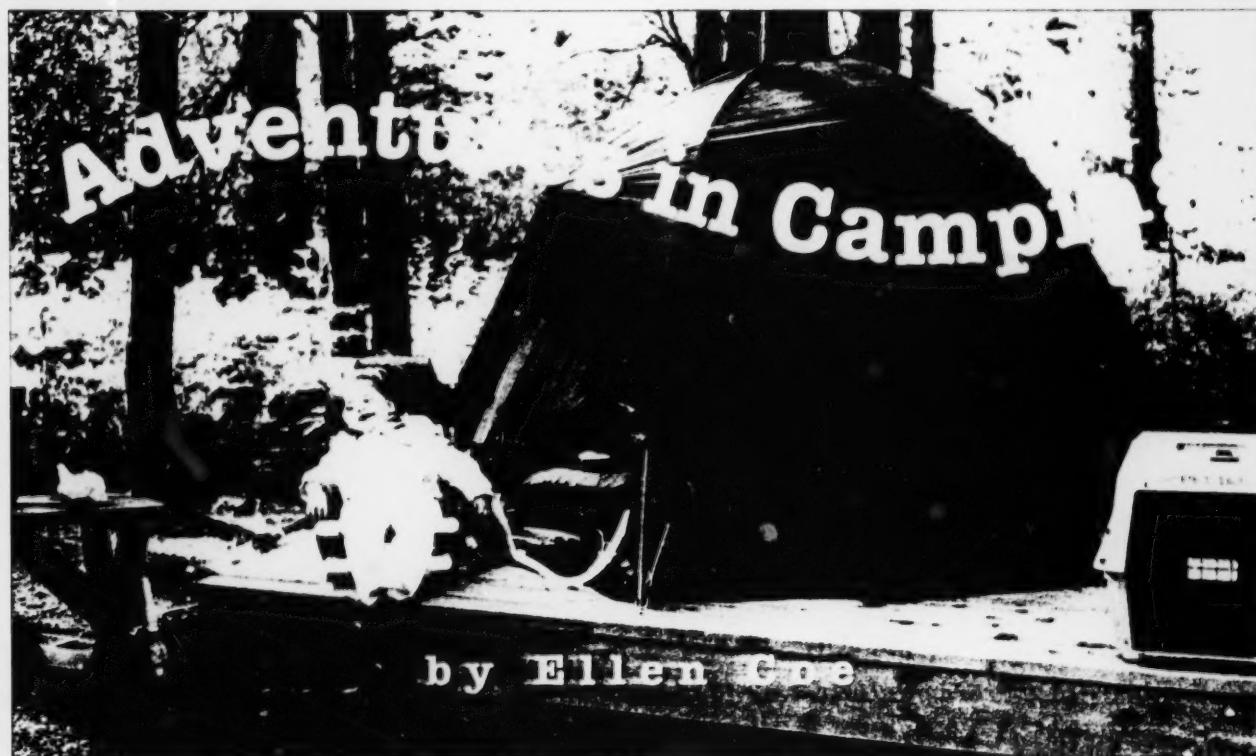
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I have always been very adventurous. One of the things I missed the most after having a child with special needs was the pleasure of camping. Michelle seemed healthy when she was born. But at two months of age she had acute encephalitis, and at five months old she quit breathing on her own. She ended up having a mass at the first vertebra in her spine.

After several major surgeries and much therapy, Michelle still depends on a ventilator to breathe and is considered an incomplete quadriplegic. She has had fairly good return of function to her hands, but they remain weak. She has had no brain damage, so she is intelligent and able to learn.

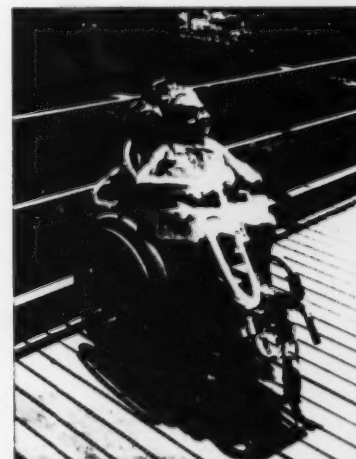
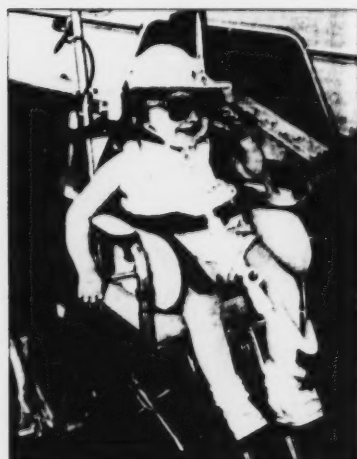
After many months of hospitalization, my first goal was to get Michelle home. As a single parent, this required getting her nursing care at home so I could

work. Following a short period of adjustment, I knew I wanted to make our lives as normal as possible within our limitations.

First Outings

Our first outings were to church. This became, and still is, a weekly routine. Soon we also began going out to the mall for short strolls. Michelle is a very happy, outgoing child and she thrived on the additional stimuli. All my friends commented on how much we were able to do.

I enjoyed being able to get out, but I was not satisfied. All this time I was struggling with lifting a safety travel wheelchair into and out of the car, while having to move the ventilator and battery as well. I realized that I needed something easier before I could enjoy frequent



trips. I traded my car in for a slightly used minivan but couldn't afford a lift. The next best thing was a collapsible ramp I had to put out and take in at every stop. I took out the middle and front passenger seats and had tie-downs installed so I could reach Michelle while driving if I needed to.

The change was dramatic. I no longer had to plan ahead of time before I went out. I put together a bag with anything we might need to go out. Also, the respiratory company made a power cord that plugged into the cigarette lighter in the car so we could run off the car battery. It gave me some peace of mind to know we wouldn't run out of power.

Camping Trips

We made a couple of overnight trips to my grandmother's house about 50 miles away. The trips went well and I enjoyed the freedom immensely. But my urge to go camping became stronger.

In May 1991, I made plans with my parents to go to northern Wyoming in their motor home. With the help of one of the nurses, I made a detailed list of what would be needed, what might be needed and what could possibly happen. Then with my van fully loaded, we headed to Casper where my parents live. After spending the night in Casper, we loaded the motor home with all the supplies and drove to the campground. With the generator in the motor home and the batteries, we had no problems running the ventilator.

The weekend was a big success. Michelle enjoyed the walks we took and sitting outside. She was able to see a horse for the first time. I was delighted but wanted more. So I began planning a trip for just the two of us and a tent. With the help of family assistance funds, I was able to buy a spare battery so we could spend more time out camping. But I still had to make plans with the ventilator's power needs in mind. The answer came in a special camp called Wilderness on Wheels, designed for people in wheelchairs. A call ahead took care of the power needs. It was a very enjoyable experience. We made a couple of other trips with my parents that summer.

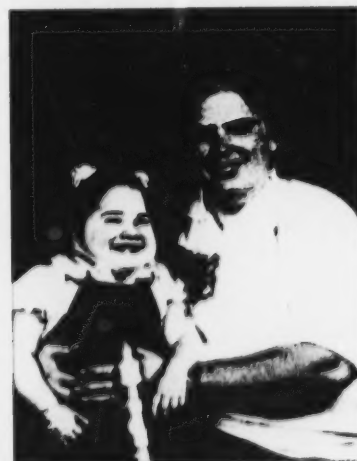
Michelle's Supplies

- backup tubing for portable ventilator, complete
- 1 complete long circuit
- extra swivel adapter
- extra trach tube
- ambu bag
- suction machine
- 2 suction catheters per day
- DeLee suction catheter
- both ventilators
- 2 airovents for nebulizer treatments
- Albuterol for nebulizers
- Cortef
- Tylenol
- Pediacare
- Benadryl
- 1, 3 and 5 cc syringes
- saline bullets
- Pediasure — 3 cans for each day
- bottles and lids
- spare battery
- battery charger
- 2 decompression tubes
- feeding tube
- oxygen tank and regulator
- oxygen tubing and connector
- heavy duty extension and power cord
- cigarette lighter/ventilator adapter cord

This summer we are already planning several week-end camping trips. As Michelle gets older, she enjoys the experience more and is able to learn more about nature. I hope that Michelle will be able to get off the ventilator in the future, but in the meantime, I am trying to make our life as "normal" as possible. EP

Wilderness on Wheels (WOW) is a nonprofit organization that promotes wilderness access for people with disabilities. Sixty miles southwest of Denver, WOW has built the first mile of a proposed seven-mile wheelchair-accessible boardwalk leading to the top of a mountain in the Pike National Forest. For more information, see story on page 36 or contact Wilderness on Wheels, 7125 W. Jefferson Ave., #155, Lakewood, Colo. 80235, (303) 988-2212.

Ellen Coe is a registered nurse in the ICU at St. Joseph Hospital in Denver, Colo. She lives in Aurora, Colo., with her daughter, Michelle, 4, who has multiple disabilities. Coe received her associate degree in nursing from Denver Community College and is currently working on her bachelor's degree through home study with Graceland College in Iowa. She is also a First Aid and CPR instructor for the Red Cross.



The Miracles of Brea



A mother explains the many difficulties and hidden rewards of having a child with multiple disabilities.

Our second child, Brea, was born three years ago with a muscle weakness. She had a club foot, a dislocated hip and some joint stiffness. She has a tracheostomy due to chronic respiratory problems and is fed via G-button because of swallowing difficulties. At night while Brea sleeps, we put her on a CPAP (continuous positive airway pressure) machine to put positive pressure into her lungs.

Brea says a few words and seems to understand almost everything. She can sit up when put in a sitting position, plays with her toys and loves books. She can scoot backwards on her bottom a little bit, but tires easily. That is the extent of her mobility. We are waiting for the insurance company to approve a wheelchair but for now we carry her everywhere. Brea is absolutely beautiful. She is happy and cheerful when healthy and entertained. She tends to get bored and irritable in the evening and it can be frustrating finally getting her to sleep. (She is very normal that way!)

Busy Days

My husband, Gil, and I work full time — he is in land surveying and I am a first-grade teacher. For

the last three years, Brea has had a nurse who arrives when I go to work and leaves when I get home. In addition to the normal household and family chores waiting for me when I get home, there are breathing treatments, lung suctioning, chest therapy and blended food therapy. There is always physical therapy to be done, not to mention cuddling and playing with Brea as well as our five-year-old, Ross, and our dog, Willie. Then, of course, there is bath time, dinner time and book time before bed. Often during the winter months, Brea has pneumonia and has to be rushed to the hospital or is at home connected to oxygen tanks with an IV in her arm. Needless to say, our stress level is high!

Making Changes & Coping

Gil and I have always been outdoors people — on the go, travelling a lot. It has been hard to lose that freedom. We like to do things as a family but sometimes Brea is just not well enough to participate. When she is well enough to join us, we choose our activities carefully because she cannot stay in one position for too long and she needs breathing treatments every four to six hours.

We try to choose things to do together that will

by Chelle Howatt

not add to our stress. We avoid large, quiet groups and indoor restaurants. We boat, bicycle and go to the beach, zoo or the homes of close friends. We have taken vacations with Brea and all of her medical equipment. It is tiring but worth it just to have a change of scenery. Sometimes we leave Brea with her grandmother and go on day trips with Ross. We are very fortunate to have my mom so close.

It is very hard to successfully deal with the stress and heartbreak of having a child like Brea. You have to be "thick-skinned" (not my strong point) and you have to be able to "transcend" the pain (I tend to be earth-bound!). Taking Brea anywhere can be very painful for me, especially when I notice people's reactions to her or watch other little girls. But, not taking her places is equally painful because she is my child and she should be there with me. I am constantly having to push aside negative and painful feelings, focusing instead on the sweetness of Brea, who she is and all the love we share. I am not denying my feelings or pain, but I do not waste too much energy on them.

Gil and I used to say maybe things will get easier. We finally realized that they probably won't. We just have to be happy with our lives now. I want to be happy and I want my family to be happy. This is a terrible blow but our lives will go on and I want them to go on happily.

Some days I have a bad attitude. I am embarrassed by my inability to handle things gracefully. On some of those days, I just go ahead and be a grump or feel sorry for myself and Brea all day. (I apologize to people later if necessary!) I cry, rant and rave — whatever I need to do. And then I feel better.

I take long runs four or five times a week. I go to church and have met a lot of supportive and inspiring people there. I read whenever I have time. I eat well, take vitamins and buy myself something nice whenever I can afford it! None of this takes away the pain but it helps me to deal with it.

Brea will have hip surgery this summer and will be



Brea, Ross and friends selling lemonade in the neighborhood.

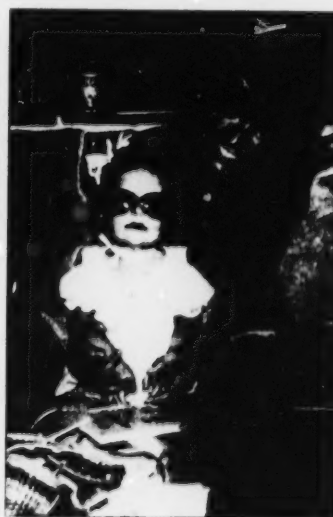
in a body cast for eight weeks. In the fall she will be attending a preschool program for children with disabilities, which will be at my school for the first time ever. We are hoping that she will be healthy enough to attend on a regular basis.

Different Kinds of Miracles

Ever since Brea was born, I have been hoping to write a miracle story — the kind where the child beats all the odds, surprises all the doctors and lives a normal life. Although that miracle has not taken place, I can see other miracles at work here — the miracle of Brea who is happy and loving in spite of all her hardships. The miracle of my husband and I — basically immature and unprepared for this crisis — handling it (sometimes ineptly and other times well). And the miracle of my little boy, Ross — happy, healthy and telling his playmate on the way home from school, "Wait till you see my sister!" **EP**



Ross and Brea catch some rays with Dad at the beach (left), while Mom and Brea celebrate Brea's second birthday (right).



Chelle Howatt lives in Palm Valley, Fla., with her husband, Gil, and children Ross, 6, and Brea, 3. Howatt is a first-grade teacher at Ponte Vedra-Palm Valley Elementary School and is a member of Palms Presbyterian Church.

Tough

Choice

by Carole Briggs
Ayres



When Andy was born, our pediatrician advised us to "treat your baby like any other child" in spite of his Down syndrome, so we assumed Andy would spend his childhood in our home and then work in the community where we live. Andy attended an integrated preschool and elementary school and the YMCA welcomed him into their after-school day-care program, including him in basketball and swimming lessons for young children.

All Was Not Well

But when Andy was in third grade, he let us know that all was not well. Day after day, his teacher and classroom aide reported that he was withdrawing when other children tried to become his friends. He hung his

head whenever I asked about it. As the year progressed, Andy began refusing to do his modified schoolwork. Instead, he demanded the exact same work his classmates were doing, even though he had no hope of understanding it. When I asked him how school was going, his frequent reply was, "I'm not smart, Mom." Often, he would shuffle to and from school, head down, looking sad. We took him to visit a child psychiatrist who felt that Andy was depressed. He started Andy on medication on a trial basis.

Andy's teacher tried to help him work on self-esteem issues. Every day, he was supposed to write about at least one good thing he had done that day, but he usually refused. His aide helped him write stories about the pets brought in from the high-school animal lab, attempting to get him to relate to animals if people were too smart or too quick for him. Andy loved the pets and the books but he still withdrew from his peers. He sat in the road on several occasions, saying he wanted to die.

As his depression worsened, Andy began destroying things he knew each of us cherished. He took a model his brother Chris had been working on and stomped it flat. Two days later, he pushed my husband Carter's word processor off its stand, breaking the monitor. The next morning, he scratched my new car and then left the door open so that the light would run down the battery. Our cheerful preschooler had become a very, very angry nine-year-old.

Running Away

Then he started running away. At first he said, "I want to see the trains," and we believed him because he usually ended up near the train tracks about two miles from our home. We took him for a train ride on his birthday, with the understanding that he would not run away to the trains again. Two hours after we returned, he disappeared. This time a neighbor found him riding his bicycle against traffic on a very busy street a mile from home. During the next two weeks, he escaped five times to play in the busy street. When we locked him in his room at night, he cut his screen and jumped out the

Photos by Carter M. Ayres

window. When I tried to talk to him about how dangerous his behavior had become, he only laughed.

On a day that gave me nightmares for weeks, a car sped into our driveway. I ran out in time to hear the driver shout, "Andy's riding in the middle of the highway and I can't get him to pull over!" Carter and I jumped into our respective cars. I spotted him first, riding straight into the oncoming cars. I pulled over and screamed, "Andy, get over here!" Grinning, Andy went around me and narrowly missed being hit by Carter. Something inside me snapped and my memory of how we got Andy over to the side of the road is completely blank. The next thing I remember is loading his bike into the back of the station wagon.

We hung his "wheels" from a hook in the garage, but six hours later, while we thought he was in bed sleeping, he released the chain locks on our doors, ran barefoot to the highway and was standing in the middle of it when the police called. By 5:30 the next morning, Andy had run away again, this time nearly getting hit by a bus. He laughed when I tried to convince him that he could have been killed. He appeared not to believe me. Or perhaps his anger had turned inward.

Hospitalization

Andy's psychiatrist agreed that he needed immediate hospitalization since he was clearly a danger to himself and possibly others if he caused a car accident. After a week in the children's unit of a psychiatric hospital, the doctor modified his diagnosis — Andy had manic-depressive illness and it was in the severe range.

He remained in the hospital for five weeks while his doctor adjusted medications. The staff took him on several outings to see if he would run away. He didn't. Still, I lived in terror that once he was discharged, he would go out and get himself killed. I had nightmares and flashbacks to the day I saw him riding into traffic. The insurance company called the hospital every other day to campaign for Andy's release.

We met with several agency people in an attempt to plan for Andy's life after discharge. Yes, we would have respite care a few days a week and yes, we could put him in a day camp when respite care ran out and in

an after-school program when school was in session. But Andy had refused friendships with children who did not have disabilities.

Weekends were long and lonely for him. I had tried to get volunteers to take him out for recreational activities, but they either quit after a few weeks or never showed up at all. Doing the job ourselves, in addition to the constant vigil for his safety, was becoming stressful beyond belief.

Residential School

Shortly after Andy's discharge from the hospital, we toured a private, residential school for children and adolescents with cognitive delays. We saw the home-like area where Andy would eat, sleep and play with 19 other boys. Andy immediately asked for a top bunk, as if he had already been accepted for admission. We learned that he would swim

three times a week in their large, heated pool and that he could play his beloved basketball in gym class and after school with regularity. Participation in recreational activities would no longer depend on people who were well-meaning, but had nevertheless come and gone from Andy's life at will, leaving a puzzled and hurt child whose self-esteem was sinking lower by the day. Woodworking, a hobby he had learned to love at home, would be part of

his daily schooling. After school and on weekends there would be Special Olympics, Cub Scouts, field trips to sporting events, miniature golf and nature hikes.

Vocational training would begin upon admission and intensify as Andy grew older. He was fascinated by the former residents who worked on campus as groundskeepers, classroom aides, cafeteria workers, greenhouse workers and farm workers. As he became ready, the

staff would rotate Andy through various jobs to see where his aptitudes and likes were and help him train for a job either on the campus or in nearby communities. Andy's comment at the end of the tour was, "I want to come here. I have work to do."

Following the tour, we applied for admission. The admissions committee agreed to let Andy attend the school on the condition that he not run away, since the school does not have fences or locked doors. For every

**Assuming that
a person with
cognitive delays and/or
emotional problems**



**will be integrated
is as big a mistake as
assuming that they
will not be integrated**

continued on page 26

mile of the 38 miles from our door to his new school. Andy asked how much longer it would be. He could not wait to begin the new life he instinctively knew would be a better one for him.

Andy Improves

After three weeks, a letter arrived from the school. I knew that it contained a report on Andy's progress and I hardly dared to open it. To my immense relief, the news was good. He was slowly beginning to allow other children to become his friends and starting to participate in classroom activities. He loved the sports program and, best of all, he had not run away even once. Two weeks later, a similar letter arrived, giving more news of steady progress in the same vein.

When Andy had been there six weeks, we visited the school for parent conferences. Both his group parent and his school teacher reported that he had three good friends, was not withdrawing and generally seemed to be enjoying himself. Now it was time for the acid test — a night at home.

We explained that we would leave his bedroom door open because we knew he was a big boy and that he had learned to stay in bed all night. He agreed. I slept well knowing that he could not escape to the highway — while Andy was in the hospital, a friend had installed indoor chain locks at the house that could actually be locked into place.

Andy did, however, have a history of melting ice cream all over the floor and stuffing the VCR with crayons at 4:40 a.m. Not this time — he slept until 6:30 a.m. When I investigated 15 minutes later, he was in the TV room watching cartoons with his brother. I praised him for his grown-up behavior. All weekend he happily played with trucks or went for a walk at the mall, staying with us. He did not ever try to run off or break anything. He behaved like a person whose needs were being met.

Two weeks later, he was officially accepted as a regular student and we received another report. This time it noted that Andy had developed some close friendships and was participating in almost all school activities. He came home for four nights at Thanksgiving and his behavior was much improved. The 10 days at Christmas went equally well. We took him to *A Christmas Carol* and to see the movie *Hook* — he loved them both. It was a joy to spend time with him when we weren't exhausted from simply keeping him alive.

The Right Decision

That winter, I attended a three-hour workshop with other parents from his school. Not one person in our discussion group had thought they would ever need to place their child outside their home. But everyone reported gains in the children's self-esteem, self-care and behavior, and felt that their family had made the right decision.

In June, we received a summary of Andy's IEP goals in addition to the progress report. Andy was still mildly depressed at times and had some inappropriate social behavior, so counseling and a behavior management program were recommended. The school's psychiatrist

would keep monitoring his medications. Andy had joined the Sign Singers because he liked signing with his nonverbal friends. Bowling and softball throw would be added to his recreational activities and he would be learning new vocational tasks. Interestingly, we noted that in gym class he was willing to try a variety of activities, but when his group made bimonthly visits to a mainstreamed gym class, Andy preferred to just watch, apparently because things moved too fast for him.

Necessary Choices

Many people with differing abilities work and live in the mainstream of society and it benefits everyone. But not everyone is emotionally able to handle integration. In addition, a dual diagnosis of a psychiatric disorder and cognitive delays can make integration extremely difficult, or — in Andy's case — impossible.

It is vital that we not lose sight of the needs of consumers and families who choose a less integrated lifestyle. Assuming that a person with cognitive delays and/or emotional problems will be integrated is as big a mistake as assuming that they will not be integrated. Residential schools can and do better meet the needs of some people, and this choice needs to be available. EP

Carole Briggs Ayres is a technical typist and copy editor at the Food Research Institute in Wisconsin. She lives in Madison, Wis., with her husband, Carter, and son, Christopher, 10. Her son Andy, 11, lives at St. Coletta School in Jefferson, Wis. *Exceptional Parent* published articles by Ayres in September 1990 and September 1988.

"Andy has become such a good self-advocate over the years that, although my husband and I hope that one day he will live and work in the community, we are aware that it will only happen if Andy decides that is best."



Dad welcomes Andy home for the weekend.



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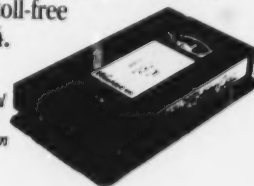
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Preserving Human Dignity

by Siegfried M. Pueschel

Siegfried M. Pueschel is director of the Child Development Center at Rhode Island Hospital in Providence, R.I. He has been involved in major research projects and clinical work in such teaching hospitals as McGill University, Harvard Medical School and Brown University. Pueschel has a Ph.D. degree in developmental psychology from the University of Rhode Island. He is married and has four children.

When I reflect on my 25 years of work as a professional in the field of human services, many significant advances and discoveries come to mind, particularly in the areas of biochemical genetics and cytogenetics where I have been most involved. However, I want to share one outstanding event that not only influenced my professional and personal life but also had a direct and indirect impact on the lives of many other people.

While I was training as a pediatric resident at Montreal Children's Hospital, my son Chris was born. My wife and I were initially devastated when we were told that Chris had Down syndrome. As was the custom at that time, we were told that he should not remain with us but should be institutionalized since he would be better off "among his own." We were informed that he would be a "vegetable," a menace to society and a disturbing factor to the lives of his brother and sister; therefore, we would be ill-advised to rear Chris at home.

There was no question in our minds that Chris would stay with us and we would bring him up in our home as we would any of our other children. In retrospect, this was one of the wisest decisions we have ever made. Like other parents who have a child with a developmental disability, we initially encountered the fundamental sorrow and despair and went through a somewhat varied "grieving process." Yet we recovered fast, adjusted fairly rapidly and soon experienced the joy and happiness Chris brought into our family.

Chris influenced my career and had a significant impact on my life. He taught me that persons with developmental disabilities have an intrinsic value of humanity and can contribute to society and perform tasks which previously were never expected of them. He taught me things I never learned in medical school or psychology courses — special children are no different from other children in their needs, only in the way they express them; they are no different from others in their rights, only in the way they can learn to use them.

Chris taught me that individuals with Down syndrome are persons in their own right, in spite of their limited capacity for academic achievements. He demonstrates every day that persons with Down syndrome

are able to learn, have fun, be responsible and dependable and work hard. He let me know that people with Down syndrome have feelings like any other human beings. They have ups and downs and will be happy when things go well and sad when they are offended or seen as second-class citizens.

Most of all, Chris taught me that an IQ score is a demeaning measure of human potential. Quality as a measure of a relationship brings a dimension that quantity cannot match. He taught me that looking upon persons with Down syndrome with respect and dignity is of utmost importance.

Chris also taught me that beyond the material accomplishments and intellectual achievements we value so highly in our culture, there are perhaps more important human qualities for which one can strive. I vividly recall an incident that occurred once while I was visiting Chris' workplace. I saw Chris taking care of a person who was blind, leading him to the dining room, helping him during coffee break and guiding him to the restroom. The kindness and patience displayed by Chris, the trust shown by the other young person and their warm interrelationship were just overwhelming.

The value of a person with Down syndrome is intrinsically rooted in his or her very humanity, in his or her uniqueness as a human being. Individuals with Down syndrome do have intrinsic value and they can reach a point of significant fulfillment of their limited potential. The complete development and satisfaction of the individual as an integrated personality should be the ultimate criteria for all human values.

Paul Wolff, a writer for the TV show *Life Goes On*, once said, "Persons with Down syndrome in some way reflect our own humanity back at us, and only our limitation causes us to fail to receive the gift. There is a goodness, humanity and magic in these persons that must be protected and never be betrayed."

It is imperative that we as parents, professionals and friends of persons with Down syndrome affirm the absolute fullness of the humanity, of the absolute worth and sanctity of their lives. Persons with Down syndrome should be offered a status that observes their rights and privileges as citizens in a democratic society and preserves human dignity.

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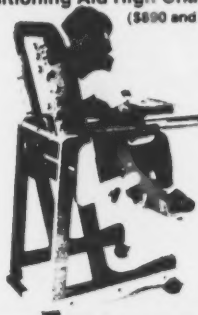
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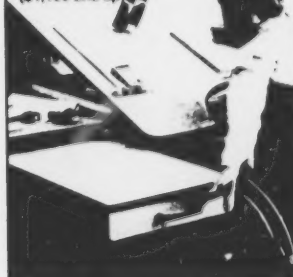


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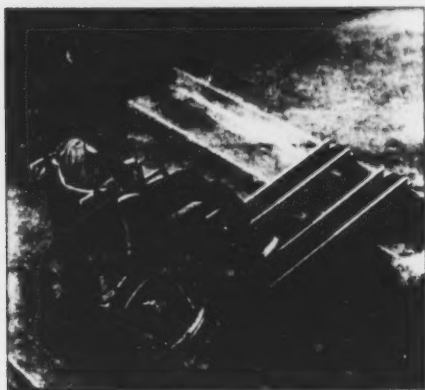
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Making Your Home Work: Ramps

Ramps are alternative routes to elevated or lowered areas for people who cannot use stairs. They do not take the place of stairs, however, since some people find ramps more difficult to use.

The American National Standard Institute's publication *The American National Standard for Buildings and Facilities — Providing Accessibility and Usability for the Physically Handicapped People* (ANSI A117.1), provides specifications for minimum standards for making buildings

accessible, including a section on ramps. When using this document, one should keep in mind that these are minimum standards which may not be adequate for making buildings completely accessible for many people.

Slope

The slope of a ramp is the most important factor to consider before installation. The ANSI specifications state that the maximum slope of a ramp should be 8.33% or 12 inches in

length for every one inch of rise (1:12). While the ANSI specifications are stated as minimum standards, many builders and designers use this as an absolute standard, and many people are still unable to independently use a ramp at this slope. Some northern states have established codes for 1:20 slopes for outdoor ramps because of the added problem of inclement weather but allow 1:12 slopes inside buildings.

The ANSI specifications state that the maximum length of a 1:12 ramp should not exceed 30 feet, but it can be longer if it has a more gradual slope. If the ramp exceeds 30 feet in length with a slope of 1:12, then a level landing area must be built midway into the ramp to provide a resting area. The landing may also be incorporated into a 90-degree angle or switchback design for very long ramps. Level landing areas should be a minimum of 5 feet wide.

Width

The width of the ramp depends on the needs of the individual and on the mobility aid used. For a person in a wheelchair, the individual's ability to control the chair and how much leeway is needed from side to side will determine sufficient width.

The minimum clear width of a ramp should be 36 inches, but if it is heavily used or routinely has two-way traffic, the width should be a minimum of 6 feet. Many designers recommend 42 to 48 inches as a standard width. The top and bottom approaches to the ramp should be level and clear for at least 5 feet.

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Low curbs, at least 2 inches high, or edges will prevent wheels from going off the sides of the ramp. The edges also provide a place to bank the wheels of a wheelchair when stopping midway on the ramp.

Surface Texture

Textural changes in the surface of the top and bottom approaches may be installed to warn pedestrians approaching the ramp. This is particularly important for persons with visual impairments.

The surface texture of a ramp should also be designed to minimize slipping in wet weather. If the ramp is wooden, the planks should run across the ramp rather than up and down. If the ramp is concrete, it should be textured. Most metal ramps are already designed to minimize slipping.

Handrails

Handrails should be installed on the sides of any ramp with a rise greater than 6 inches. The distance



EZ-Access Roll-Up™ portable ramp by Homecare Products.

across from one rail to the other will be narrower than the ramp and will depend on the personal comfort of the user.

Handrails are usually installed 36 inches above the ramp, but a second handrail can be installed at 28 inches for children and people in wheelchairs. Handrails should extend 12 inches beyond the top and bottom of the ramp. The handrails can be square or round in shape,

with round being preferred if the user is going to be holding on most of the time.

Outdoors

Outdoor ramps and their approaches should be designed so water will not accumulate on the surface. Anti-skid or textured surfaces can be added to ramps, but weather conditions should be considered. Some surfaces make it difficult to clear the ramp of snow and ice, and some surface treatments may increase resistance thus requiring

greater energy output. A canopy can be built over ramps exposed to inclement weather and heating coils can be built-in to melt ice and snow in cold climates.

Modular Ramps

There are many styles of modular metal ramps that can be purchased ready to install. Modular ramps have the advantage of being more easily moved to another location if necessary.

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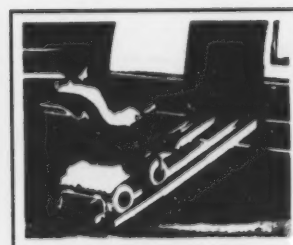
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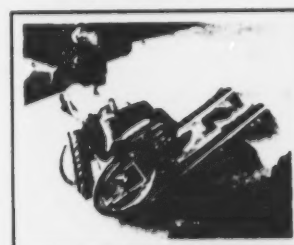
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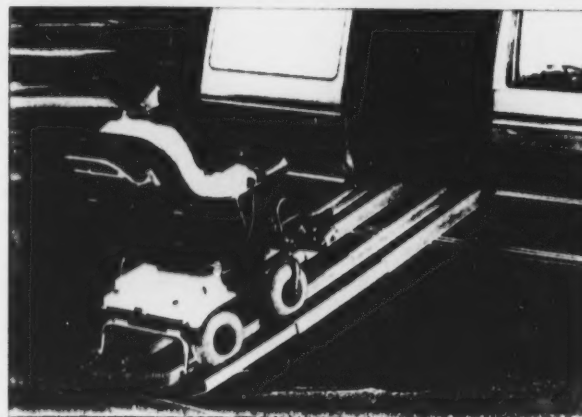
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ramps are permanent while metal and wood can be considered semi-permanent. Commercially available modular ramps come in sections of various sizes that can be dismantled. All ramp materials should be fire-proof.

Portable Ramps

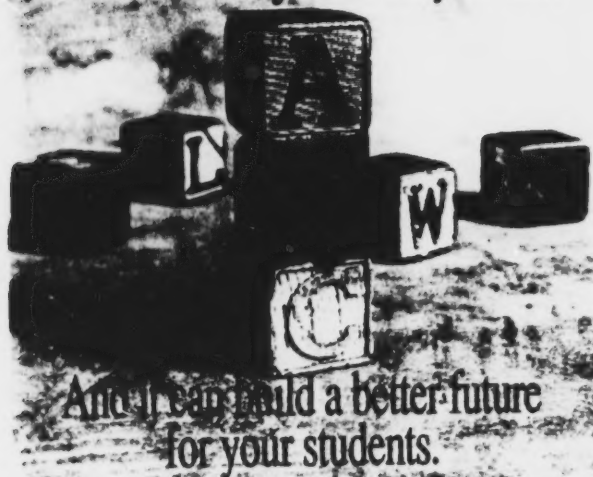
Portable ramps are also available. Depending on the skills of the individual who needs the ramping, another person may be needed to set up the portable ramp. Portable ramps are relatively short in length with a standard width but they are made of a lightweight material, or they can be folding tracks wide enough for the wheels of a wheelchair. When using folding track-type ramps, two ramps are required and they must be carefully positioned each time they are used.

Track or telescoping ramps consist of two separate channels for the wheels of a wheelchair. Channels come in various lengths and are usually hinged for folding and carrying. Sometimes the channels telescope into each other for transport. These tracks can only be used by four-wheeled chairs, not three-wheel scooters.

*This article has been adapted from ABLEDATA Fact Sheet, number 6, January 1990, entitled **Ramps**. ABLEDATA is located at the National Rehabilitation Information Center (NARIC). NARIC is a library and information center in disability and rehabilitation. NARIC collects and disseminates the results of federally-funded research projects. The NARIC collection also includes commercially published books, journal articles and audiovisuals. NARIC manages the REHABDATA bibliographic database, which contains citations and descriptions of the material in the collection.*

For copies of the fact sheet (single copies are free) or more information, contact ABLEDATA, 8455 Colesville Rd., Suite 935, Silver Spring, Md. 20910-3319, (800) 227-0216 or (301) 588-9284 or call ABLE INFORM, an electronic BBS, at (301) 589-3563 with the modem settings 2400 baud, 8-N-1. Both ABLEDATA and NARIC are funded by the National Institute on Disability and Rehabilitation Research (NIDRR), with contracts numbers HN92026001 and HN90028001, respectively. Both are operated by Macro International, Inc.

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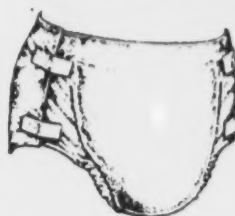


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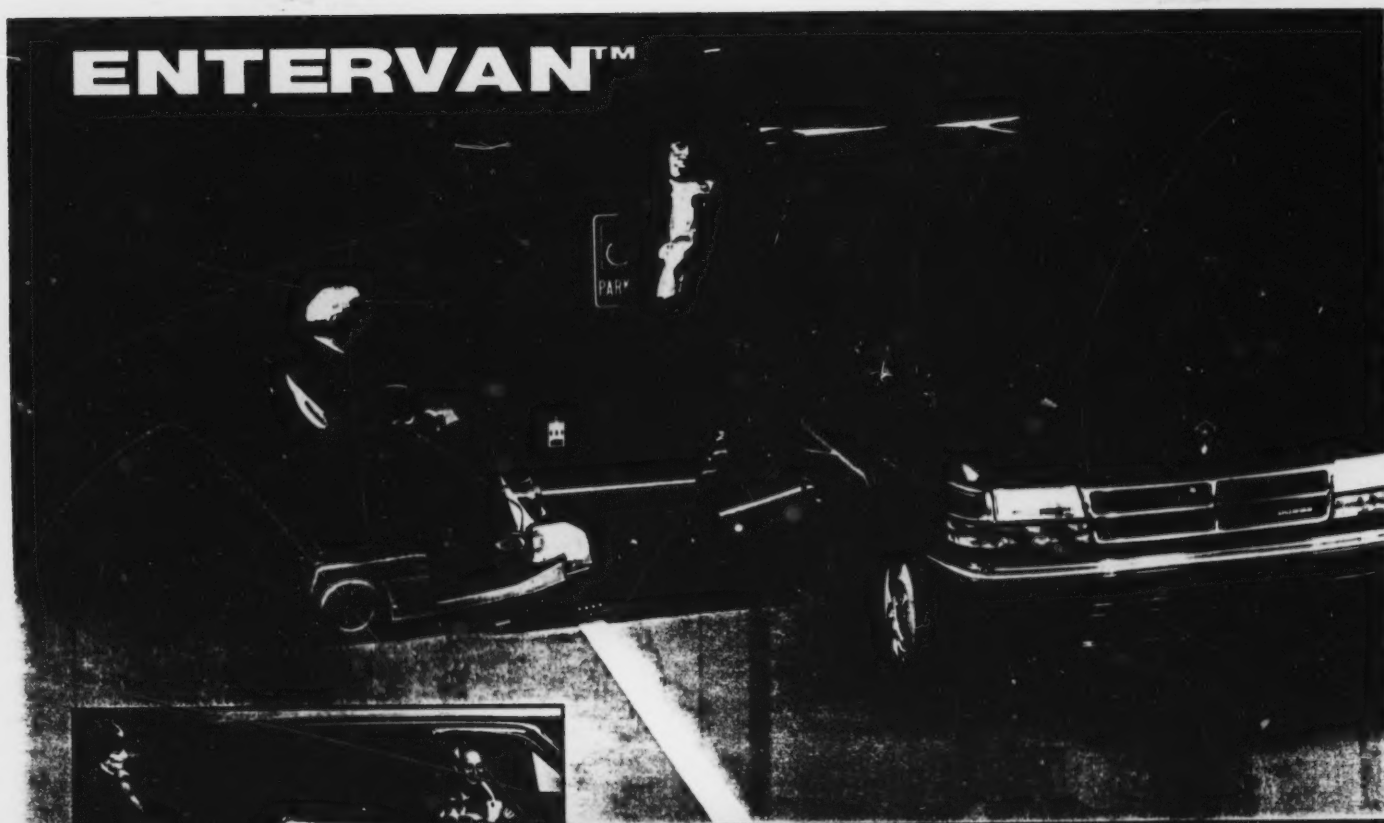
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Horseback Riding Can Be Therapeutic

Like many sports, horseback riding has risks as well as rewards, and for a rider with a disability, these risks are accompanied by particular obstacles. This is why the North American Riding for the Handicapped Association (NARHA) was formed.

As the governing body for the therapeutic riding industry, NARHA, a nonprofit organization operating since 1969, establishes safety standards and teaching techniques for its operating centers. This means that each rider is assured the greatest reward with the least possible risk.

Research shows that therapeutic riding can produce physical, emotional and mental rewards. For individuals with impaired mobility, horseback riding gently and rhythmically moves their bodies in a manner similar to a human walking gait. These riders experience increased balance, muscle control and strength.

Individuals with learning disorders or mental disabilities are motivated by riding to increase concentration, patience and discipline. All riders benefit from increased self-esteem and confidence.

For more information, contact the North American Riding for the Handicapped Association, Inc., P.O. Box 33150, Denver, Colo. 80233, (800) 369-RIDE, (303) 452-1212.

Travel Guide Offers More Than the Usual

The Real Guide: Able To Travel is a collection of more than 100 tales by travelers with disabilities describing

their adventures, their setbacks and their triumphs.

The book covers the globe. Not everything can be accessible, but *The Real Guide: Able To Travel* demonstrates just how much potentially is and makes a powerful case for removing all barriers, both physical and communicative, encountered by travelers with disabilities. In addition to the stories, a planning section based on the experiences of real travelers covers all you need to know before you go, including choosing an airline, finding a hotel and taking care of your medical needs overseas.

The book's stories inform and inspire: a wheelchair user explores Mayan culture in Honduras and the cloud forests and beaches of Costa Rica and a teacher who is quadriplegic seeks out the literary Ireland of Joyce and Yeats.

Available at most national bookstore chains.



Wilderness Now Accessible to All

Wilderness on Wheels (WOW), a nonprofit organization, is a model wilderness access facility being developed to provide access for people with disabilities to natural environments.

WOW's goal is to build an eight-foot wide boardwalk to the top of the north cone of Twin Peaks in the Pike National Forest. After six years and 60,000 volunteer hours, the first mile has been completed. Once completed, the trail will stretch seven miles to the top of the mountain.

In addition to the trail, accessible camping sites have been built. Tent decks elevated to the height of a wheelchair seat are complemented by elevated cooking grills. There are

also picnic tables and accessible rest rooms available. Dogs are not encouraged, but those required must be restrained on short leashes. There is no charge for use of the area, but donations are requested because WOW is funded solely by donations.

WOW, located 60 miles southwest of Denver, Colo., is open from mid-April to mid-October by reservation.

For more information, contact Wilderness on Wheels, 7125 W. Jefferson Ave., #155, Lakewood, Colo. 80235, (303) 988-2212.



Wilderness Inquiry Shares Outdoor Adventures/Travel

Wilderness Inquiry, a nonprofit organization, started in 1978 with a desire to share outdoor adventure travel with people from all walks of life. Since that time, it has served more than 10,000 people on countless trips throughout North America, Europe and Australia.

These adventures are open to people of all ages and abilities, including people with sensory, cognitive or mobility impairments. Options include skiing, dogsledding, canoeing, paddling or kayaking.

For more information, contact Wilderness Inquiry, 1313 Fifth St. SE, Box 84, Minneapolis, Minn. 55414-1546, (612) 379-3858.

Resort Fills Special Vacation Needs

Situated on 40 acres of spruce trees and tranquil inlets, Bancroft/Owl's Head has served as a summer camp for children and adults enrolled in Bancroft programs since 1904.

Recognizing the need for a resort where individuals with disabilities can vacation with their families, Bancroft has added to its camp program a vacation resort plan for families wishing to explore the coast of Maine or relax in the fresh air of coastal New England.

Accommodations include accessible rustic cabins and bayfront cottages.

For more information, contact Joseph Kuhn, Bancroft/Owl's Head, Lighthouse Road, Owl's Head, Maine 04854, (207) 594-7261.

MDA Camps Knock Down Barriers

Since 1955, the Muscular Dystrophy Association's (MDA) extensive camp program has built bridges and knocked down barriers, fostering a sense of self-worth in young people with disabilities and greater understanding in able-bodied counselors.

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MDA camp programs, although structured, are conducted in a relaxed atmosphere that gives campers an opportunity to develop lifelong friendships, share interests and build self-confidence.

Activities range from outdoor sports such as swimming, boating and baseball to less physically demanding programs like arts and crafts and talent shows.

For more information, contact the Muscular Dystrophy Association, National Headquarters, 3300 E. Sunrise Dr., Tucson, Ariz. 85718.

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(800) 225-7361

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Directory of Advertisers

Advertiser	Page #	Advertiser	Page #
AAMR	19	Homecare Products, Inc.	31
AccessAble	30	HMS School	65
Adaptive Designs	39	Hoening Mobility	39
Anne Carlson	61	Innovative Products	19
Aquatic Therapy	41	Jay Medical	5
Beebop	45	Jesana	29
Berkshire	57	Kid Kart/Kid Care	9
Bissell-JA Preston	back cover	League School	65
Braun	34, 35	Marblesoft	33
Bruno	27	Martha Lloyd	59
Cardinal Cushing	60	Mobility Tech. Corp.	39
Charles C. Thomas	51	Nesheeka	49
Chrysler	2	New England Center for Autism	55
Cindylift	45	New England Villages	64
Columbia Medical	13, 15	Pathfinder	64
Consumer Care	29	Phonic Ear	12
Convaid	11	Prentke Romich	33
Cotting School	60	Porter Sergeant	66
Crystal Springs School	65	Quickie Designs	1
Devereux	62	R.J. Cooper	13
EP Book Ad	45	Racing Strollers	29
EP Book Ad	inside back cover	Roleez	49
EP Book Ad (Lash)	44	Sentient Systems	7
EP Subscription Strip	39	Snug Seat	10
Equipment Shop	33	St. Coletta School	55
Estate Planning	45	St. John Villas	64
Flaghouse	49	Stewart Home	65
Flinchbaugh	41	TASH	49
Ford	inside front cover	Totokiki USA	27
Havench Ortho Sport	41	Woodbury Products	41
HDIS	33	Woodie Services	64
Heartspring	63		



Easter Seal Society's Accessible Camps

The following camps are run by the local Easter Seal Societies in each state. They are all accredited by the American Camping Association (ACA). The camps offer a variety of mainstreamed and non-mainstreamed programs. For help in choosing the right camp for your child, contact your local Easter Seal Society for a free copy of the brochure *Make the Right Choice for Your Child — Camps for Children with Disabilities*. Or send a self-addressed, stamped envelope to: The Communications Department, National Easter Seal Society, 70 E. Lake St., Chicago, Ill. 60601.

ALABAMA

Camp ASCCA
Jerry Bynum
Administrator
P.O. Box 21
Jackson's Gap, AL 36861
(205) 825-9226

ALASKA

Camp Caribou
Alaska Easter Seal Society
3719 Arctic Blvd.
Anchorage, AK 99503
(907) 561-7325

ARIZONA

Camp Easter Seal
Beth Lucas
903 N. Second Ave.
Phoenix, AZ 85004
(800) 626-6061

CALIFORNIA

Camp Easter Seal
Brian Bost, Director
Easter Seal Society of the
Inland Counties
241 E. Ninth St.
San Bernardino, CA 92410
(714) 888-4125

Camp Harmon
Jane Carr, Director
Easter Seal Society
of Santa Cruz, Monterey
9010 Soquel Dr.
Aptos, CA 95003
(408) 684-2166

Camp Lisa
Kerry Ann McArtney
P.O. Box 1035
Healdsburg, CA 95448
(707) 433-5402

COLORADO

Easter Seal Handicamp
Mellode Lowther, Director
P.O. Box 115
Empire, CO 80438
(303) 569-2333

CONNECTICUT

Hemlocks Recreation Ctr.
Sunny Ku, Director
P.O. Box 198
Hebron, CT 06248
(203) 228-9496

FLORIDA

Camp Challenge
Jesse Shuman, Director
31600 Camp Challenge Rd.
Sorrento, FL 32776
(904) 383-4711

ILLINOIS

Camp Heffernan
Tim Furey, Administrator
Easter Seal Center
206 S. Linden, Suite 4A
Normal, IL 61761
(309) 452-8074

Easter Seal Camp
Richard Merz
Executive Director
Easter Seal Rehab. Ctr.
1230 N. Highland Ave.
Aurora, IL 60506
(708) 896-1961

INDIANA

Camp Koch
Tom Wellman, Director
Easter Seal of Indiana
P.O. Box 39
Troy, IN 47588
(812) 547-5581

Isanogel Center
Cindy Lloyd, Director
7601 W. Isanogel Rd., #50N
Muncie, IN 47304
(317) 288-1073

IOWA

Camp Sunnyside
Pete Theisman
Dir. of Camping/Recreation
P.O. Box 4002
Des Moines, IA 50333
(515) 289-1933

KENTUCKY

Camp Kysoc
Heidi Miller
Director of Camping and
Recreation
233 East Broadway
Louisville, KY 40202
(502) 584-9781

MARYLAND

Camp Fairlee Manor
Mike Currence
Program Director
22242 Bay Shore Rd.
Chestertown, MD 21620
(410) 778-0566

MAINE

Pine Tree Camp
Greg Ouellette
Executive Director
84 Front St.
Box 518
Bath, ME 04530
(207) 443-3341

MASSACHUSETTS

Agassiz Village
Rosalind Fisher
Camp Coordinator
484 Main St.
Worcester, MA 01608
(508) 757-6343

NEBRASKA

Camp Easter Seal
Deb Waskowiak
Executive Director
3015 North 90th Street
Suite 6
Omaha, NE 68134
(402) 571-2162

NEW HAMPSHIRE

Camp Easter Seal
Lisa Lambert
Executive Director
555 Auburn St.
Manchester, NH 03103
(603) 623-8863
(Please see page 16 for
more information)

NEW JERSEY

Camp Merry Heart
Mary Ellen Ross
Executive Director
RD #2, O'Brien Road
Hackettstown, NJ 07840
(908) 852-3896

NEW MEXICO

Camp Easter Seal
Attention: Director of Camp
Easter Seal
2819 Richmond Dr. NE
Albuquerque, NM 87107
(505) 888-3811

NEW YORK

Camp Goodwill
Robert O'Brien, Director
N.Y. Easter Seal Society
Rt. #1, Falls Boulevard
Chittenango, NY 13037
(315) 655-9735

NORTH CAROLINA

Easter Seal Camp Program
Karen Hamilton, Jeff Smith
N.C. Easter Seal Society
2315 Myron Dr.
Raleigh, NC 27607
(919) 783-8898

OKLAHOMA

Camp Easter Seal
Toni Butler, Director
2100 NW 63rd Street
Oklahoma City, OK 73116
(405) 848-7603

OREGON

Camp Easter Seal
Diane Battaglia, Camp Mgr.
3575 Donald St.
Eugene, OR 97405
(503) 344-2247

PENNSYLVANIA

Camp Harmony Hall
Richard Lewis, Director
P.O. Box 497
1500 Fulving Mill Rd.
Middletown, PA 17057
(717) 939-7801

TENNESSEE

Camp Easter Seal
Johnny Ambrose, Director
Easter Seal Soc. of Tenn.
2001 Woodmont Blvd.
Nashville, TN 37215
(615) 251-0070

VIRGINIA

Camp Easter Seal
Eric Dresser, Director
4841 Williamson Rd.
P.O. Box 5496
Roanoke, VA 24012
(703) 362-1656

WASHINGTON

Camp Easter Seal
Mary Jo Morykon, Director
P.O. Box J
Vaughn, WA 98394
(206) 884-2722

WISCONSIN

Camp Wawbeek
Matt Anderson, Director
Wis. Easter Seal Society
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Dealer inquiries invited



Specialized Hospital Camps

The following listing contains the addresses and phone numbers of camps that provide specialized services for children with disabilities. These camps are sponsored by hospitals which belong to the National Association of Children's Hospitals and Related Institutions, Inc. (NACHRI). This listing was produced by NACHRI, 401 Wythe St., Alexandria, Va. 22314, (703) 684-1589.

CONNECTICUT

Hole in the Wall Gang Camp
James Schaffer, Director
555 Long Wharf Dr.
New Haven, CT 06511
(203) 772-0522

FLORIDA

The following camps are sponsored by the Miami Children's Hospital, 6125 SW 31st Street, Miami, Fla. 33155, (305) 666-6511:

Arthritis
Beth Bridy
Division of Rheumatology
Cottage #3
(305) 663-8505

Asthma
Brian Hannigan
Education/Staff Dev.
(305) 666-6511, ext. 2516

Diabetes
M. Iliana Sanders
Division of Endocrinology
MOB #303
(305) 662-8398

Oncology
Maria Campbell
Division of Hematology/
Oncology
MOB #104
(305) 662-8360

VACC
Cathy Klein
Div. of Pediatric Pulmonology
3200 SW 60 Court, Ste. 203
Miami, FL 33155
(305) 662-VACC

GEORGIA

Camp Sunshine
(for oncology patients)
Sally Hale
Scottish Rite Medical Ctr.
P.O. Box 77236
Atlanta, GA 30309
(404) 872-6977

INDIANA

Champ Camp
(for children with tracheostomies or who require ventilator assistance)
Lifelines Children's Rehabilitation Hospital
P.O. Box 40407
Indianapolis, IN 46240-0407
(317) 872-0555

KENTUCKY

Camp Superkids
(for children with asthma)
American Lung Association
Menisa Marshall
P.O. Box 9067
Louisville, KY 40209
(800) 366-LUNG
(502) 363-2652

MASSACHUSETTS

Camp Chest Nut
American Lung Association of Massachusetts
Barbara O'Neil
803 Summer St.
Boston, MA 02127
(617) 269-9720

Clara Barton Camp
(for girls with diabetes)
Shelley Yeager
Executive Director
P.O. Box 356
North Oxford, MA 01537
(508) 987-2056

Elliot P. Joslin Camp
(for boys with diabetes)
Joslin Diabetes Center
One Joslin Place
Boston, MA 02215
(617) 732-2455

PKU Camp
Beth DeAngelis
PKU Program
Gardner 816
Children's Hospital
300 Longwood Ave.
Boston, MA 02115
(617) 735-7346

Edward J. Madden
Memorial Open Hearts
Camp
Ken Coulon
250 Monument Valley Rd.
Great Barrington, MA 02130
(413) 528-2229

MICHIGAN

Camp Copneconic
National Kidney Foundation of Michigan
2350 S. Huron Parkway
Ann Arbor, MI 48104
(800) 622-9010
(313) 971-2800

MINNESOTA

Camp Ozawizeniba
(for children and teens ages 8-18 who have epilepsy)
Camp Oz
Gillette Children's Hospital
777 Raymond Ave.
St. Paul, MN 55114
(800) 779-0777
(612) 646-8763

S.K.I.P. Camp
(for children who are dependent on technology)
Barbara Donaghy
Children's Hospital
11208 Minnesota Mills Rd.
Minnetonka, MN 55343
(612) 220-6027

NEW HAMPSHIRE

Camp Sunrise
(for children with cancer)
American Cancer Society
New Hampshire Division
360 Route 101, Unit 501
Bedford, NH 03110
(603) 472-8899

NEW JERSEY

AAC Camp
(for children using augmentative and alternative communication systems)
Joan Bruno
Camp Coordinator
Children's Specialized Hospital
150 New Providence Rd.
Mountainside, NJ 07092
(908) 233-3720

NEW YORK

52 Association for the Handicapped
(a skiing clinic designed for children with amputations)
Allan D. Weinberg
350 Fifth Ave., Rm. 7710
New York, NY 10118
(212) 563-9797

OHIO

The following camps are sponsored by the Children's Hospital Medical Center of Akron, 281 Locust St., Akron, Ohio 44308, (216) 379-8200:

ACBC Summer Camp
(for children recovering from burns)
Marie Worrell
Cheryl Sanders
(216) 379-8813

Camp Ability
(for children with spina bifida)
Debbie Gibson
Geri Pallija
(216) 379-8195

Camp CHOPS
(for children with cancer, leukemia and related blood conditions)
Nancy Carst
Elizabeth Morstatter
Pam Cicora
Charlene Maxen
(216) 379-8830

Camp Wonderlung
(for children with asthma)
Debbie Ouellette
Dianne Fihe
(216) 379-8585

Certified Fun Camp
(for children with cystic fibrosis)
Cathie Lippencott
Betsy Maxwell
(216) 379-8545

The following camps are sponsored by the Children's Hospital, 700 Children's Dr., Columbus, Ohio 43205, (614) 461-2000:

Cystic Fibrosis Camp
Margaret Pease
(614) 461-2515

Hematology Camp
Roz Williams
(614) 461-2460

Kidney Camp
Beth Smith
(614) 461-2166

Myelomeningocele/Rehabilitation Camp
Dennis Brazelton
(614) 461-2833



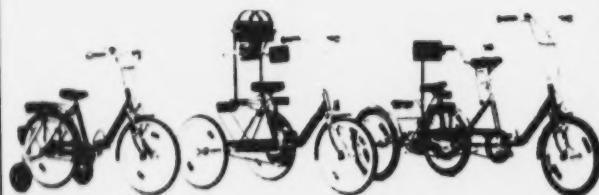
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Keene, NH 03431 (603) 358-0438

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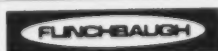
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RESOURCE SECTION

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Barbara Rushley
Central Ohio Lung Assoc.
4627 Executive Dr.
Columbus, OH 43220
(614) 457-4570

Camp Allyn
(for children and adults with any disability)
Renie Taylor, Director
5650 Given Rd.
Cincinnati, OH 45243
(513) 831-4660

Camp Cheerful
(for children and adults with physical, medical and language disabilities)
David Mable
Administrative Director
Dee Mable
Program Director
1500 Cheerful Ln.
Strongsville, OH 44136

Camp Christopher
(for children with mental retardation)
Catholic Youth Organization of Summit County
404 Elbon Ave.
Akron, OH 44306-1500
(216) 773-0426

Camp Courageous
(for children with mental retardation)
Rick Rinestine, Director
1 Stranahan Sq., Ste. 540
Davis Building
Toledo, OH 43604
(419) 242-4412

Camp Ko-Man-She
(for children with diabetes)
184 Salem Ave.
Dayton, OH 45406-5877
(513) 220-6111

Camp Mohaven
(for children with cystic fibrosis)
Marilyn Butschillinger
The Children's Medical Center
One Children's Plaza
Dayton, OH 45404-1815
(513) 226-8376

Camp Superkids
(for children with asthma)
Kathy Prosser
American Lung Association
1700 Arlingate Ln.
Columbus, OH 43228
(614) 279-1700

Camp Wanake
(for children with mental retardation)
Jim Parkhurst
Director
9463 Manchester Rd., SW
Beach City, OH 44608
(216) 833-9924

Camp Wekandu
(for children with rheumatic diseases of childhood and adolescence)
Pam Heydt
Div. of Rheumatology
Special Treatment Center for Juvenile Arthritis
Children's Hospital
Elland and Bethesda Avenues
Cincinnati, OH 45229-2899
(513) 559-4676

Diabetes Camp
Lori Saunier
Central Ohio Diabetes Association
1580 King Ave.
Columbus, OH 43212
(614) 486-7124

Highbrook Lodge
(for children and adults with visual impairments)
Cleveland Sight Center
1909 East 101st Street
P.O. Box 1988
Cleveland, OH 44106
(216) 791-8118

Kappa Kidney Kamp
(for children ages 8-18 who have had kidney transplants or are experiencing kidney or urinary tract dysfunction)
Stephanie Evans, Director
1373 Grandview Ave.
Suite 200
Columbus, OH 43212
(614) 481-4030

Matthew Salem Camp
(for children with asthma, chronic lung and/or respiratory disease)
2211 Arthur Ave.
Lakewood, OH 44107
(216) 228-0334

Recreation Unlimited
(for children and adults with all disabilities, including mental retardation)
Gary Bertelsen
Development Director
7700 Piper Rd.
Ashley, OH 43003
(614) 548-7006

YMCA Camp Kern
(for children with juvenile arthritis, muscular dystrophy, cancer)
Larry L. Maxwell
John Fieley
5291 State Route 350
Oregonia, OH 45054
(513) 885-3807

OKLAHOMA

The following camps are sponsored by the Oklahoma Medical Center, P.O. Box 26307, Oklahoma City, Okla. 73126, (405) 271-3600:

Cystic Fibrosis
Debbie Berry
Pulmonary Nurse
Clinician
(405) 271-6086

Diabetes
Dr. Tom Lera
(405) 271-4407

Hematology/Oncology
Lori Lunsford
(405) 271-4518

Hemophilia
Beverly Stevens
(405) 271-3661

Kidney Camp
Cindy Stern
(405) 271-4518

Meningomyelocele
Dr. Harriet Coussons
(405) 271-5700

Children dependent on ventilators
Debbie Berry
Pulmonary Nurse
Clinician
(405) 271-6086

PENNSYLVANIA

Handi*Camp
(for children, teens and young adults with disabilities)
237 Fairfield Ave.
Upper Derby, PA 19082
(215) 352-7177

Heart Camp
(for children ages 8-14 with heart disease)
Cardiology Department
Children's Hospital of Pittsburgh
3705 Fifth Ave.
Pittsburgh, PA 15213
(412) 692-5540

TENNESSEE

Camp Eagle's Nest
(for oncology/hematology clinic patients ages 6 & older)
Laura Barnes
East Tennessee Children's Hospital
2018 Clinch Ave.
Knoxville, TN 37901
(615) 541-8000

TEXAS

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(for cancer patients and their siblings, ages 7-14)
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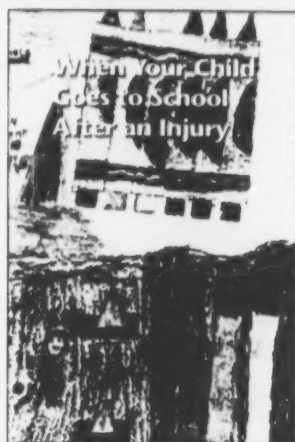
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WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY

by Marilyn Lash, M.S.W. Published by *Exceptional Parent*, in collaboration with the Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center, ©1992 Tufts University. For information about purchasing *When Your Child Goes to School After an Injury*, see below.

The following excerpt is from the chapter *From Hospital to School* by M. Lash and K. King.

Becoming your child's service coordinator

Injured children need many different services as they grow and recover. A case manager is a professional, usually a social worker, rehabilitation nurse, or physician, who arranges and coordinates multiple services. This person may be employed by a hospital or insurance company. Case managers are also used by state and community agencies. Schools may provide case managers through special education teachers, therapists, social workers, guidance counselors, or nurses.

It is the family, however, who finally becomes the child's case manager or service coordinator, because professionals and programs change over time. Below are practical steps you can take to be effective as your child's service coordinator.

- Record the names, addresses, and telephone numbers in a notebook of everyone who treats, tests, or examines your child.

- For any report written on your child, ask that a copy be sent to you. Many parents use a filing system of medical, educational, psychological/emotional and social/recreational categories.

- Keep notes on important telephone conversations.

- Use a 18- to 24-month calendar or date book for scheduling appointments.

- Do not end a meeting without summarizing aloud the discussion and suggestions. Make sure you have understood everything said, especially unfamiliar terms.

- Find a "buddy" or partner. Some parents found it very helpful to share all information and meetings with one person. Most people think of their spouses, but it can be anyone — friends, in-laws, or relatives.

Why do this?

- It is hard to remember everything when you are tense, nervous or upset.

- A non-parent can be more objective.

- It is another resource for listening and problem solving.

- In case something happens to you, someone else will be prepared to help your child.

- Gather any written information, even if you are not sure when or how you will need it.

- Keep a resource file or information box for newspaper clippings, magazine articles, pamphlets or information sheets.

- Use all available resources.

Parents often do not contact organizations for children with special needs or other disabling conditions or illnesses. However, these organizations often have staff, and frequently have trained parents, who work with schools and help develop special education plans. Their knowledge of the process and skills in negotiation can help guide you.

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Volume 1, Number 1, Spring 1993

The Best Interests of the Child

A National Issue — A Local Dilemma

by Barry Romich

Although this article discusses communication, the problem affects all children. Based on reports we have heard, the planned withholding of needed services and equipment, educational and/or therapeutic, is one way that local officials have tried to cut costs. Because of the pressure to reduce costs, sometimes more subtle withholding of services takes place. In fact, some professionals lose sight of the fact that they are recommending less than adequate care because of the stresses imposed by financial limitations.

Parents and their advocates at the local level, as well as state directors and their legal counsel, must monitor the ways IEPs are created and carried out to assure that needed services and equipment are provided. Within such a monitoring system, parents or professionals who believe that decisions are being made based on local constraints rather than a child's needs must have confidential mechanisms for lodging complaints without creating trouble for themselves or their loved ones.

A relatively small segment of our students with disabilities must rely on augmentative and alternative communication (AAC). To participate meaningfully in the education process, these students need certain special services. In addressing the needs of these students, special language professionals, such as communication specialists, must be available. Unfortunately, some districts have no such services.

Unfortunately, it is common for professionals who have been trained not to do this (no determination by the student's IEP team) to be asked (often by the school or publisher) to do it. I state that an AAC system will be purchased on the basis of our future (non)function. However, different systems allow significantly different levels of functional communication and hence, personal achievement. The potential for sound clinical practice by the professional (and team members) involved or communication itself directly can be determination of employment.

When this occurs, two things happen. The first, usually violates one of our code of ethics which states that the interests of the student being served should be held paramount. And then, perhaps worse, this violation is kept secret. No one knows that the right thing has not been done. Parents are usually completely dependent on the expertise of school personnel in determining appropriate services. The parents are not aware that the best possible services are not being provided and that the student's future levels of personal achievement will be adversely affected.

This practice is clearly wrong as well as illegal. First, it is a violation of the federal IDEA. Second, it is a violation of the state's professional code of ethics and training. Many parents, by contrast, do not

know in mainstreamed classrooms. My experience has been that "mainstream" students require the school to hold off. Years in many years, I have seen students go on to college and obtain competitive employment.

Students who do not receive AAC services and training continue to need significant assistance from personal aides. They move from grade to grade without academic or personal growth and seem destined to live in custodial settings for their lifetimes. The obvious costs for failure far exceed the costs of success.

Sadly, although this practice is clearly illegal, many families do not go on to due process hearings because they are intimidated, they do not want to create adversarial relationships with professionals or they are unaware that an alternative for success may be available.

My observations suggest that this practice of refusing to provide appropriate services appears to be made on the local school district level, rather than on the state and professional levels. In my career, I have had the opportunity to meet school board directors and their legal counsel, officers, or administrators. I believe that it is at the local level that students come in contact with this

problem. It would be a matter of increasing national meetings so that the personnel responsible for special services at the local levels, including their local representatives, the roughly hundred thousand local and local level educators, might come together to write local policy, rather than to tell what assessment steps should be followed to determine the appropriate technology. How to set realistic educational goals for the student using technology, what are the legal responsibilities of the parties involved, etc.



Barry A. Romich co-founded Romich Romich Company in 1986 and currently serves as its Chairman and CEO. The company is based in Houston, Texas, provides augmentative and alternative communication equipment, training, and a training program of the International Society for Augmentative and Alternative Communication as well as the United States Society for Augmentative and Alternative Communication. He is also a past president of the International Society for Augmentative and Alternative Communication.



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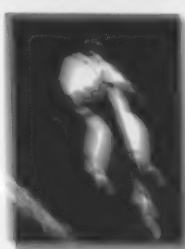
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We recently invited Alliance for Technology Access centers to submit success stories describing individuals or families who have incorporated technology into their lives. This is Exceptional Parent's third installment of these stories.

In study 2, the 100 most commonly used ATA tasks were identified and categorized by difficulty level. The 100 tasks were then used to represent a list of the many products demonstrated and used at ATA centers.

ATA Scrapbook of Success

From slow learner to honors student

From a parent at our ATA center in Jackson, Tenn.: The West Tennessee Special Technology Resource Center (STARC) was the answer to our concerns about our 12-year-old daughter, Amy, who has retinitis pigmentosa. We discovered she had this eye disorder when she was 10 years old. Shortly after the diagnosis, our pediatric ophthalmologist referred her to

The first month that Amy left to prepare for the implementation of Amy's self-esteem. She was a kindergarten learner for many years. The teachers and a psychologist said Amy was a slow learner. When she started using the computer, her grades have gone up and she has made the honor roll.

job when she gets older. She is also learning which tools she can use if her vision deteriorates.

Student/Teacher:

[illegible]

Each summer at the University of Arizona, I have a special opportunity to work with the local Hispanic and programming community. The students and faculty in



John's suffering gained him respect, and he became a leader among the poor.

During the past year, and gained from the reports of teachers and students and, as a result, he entered high school with confidence and energy.

John is currently working in the high school computer lab as a teacher assistant and recently initiated a computer-aided instruction program. He is looking forward to a future in which computers will play a useful and vital

•••••

Elizabeth Hackett is a 26-year-old woman with mental retardation. The challenge has been to find funds to help her learn. When she was in school, her family was told that she would stop learning at age 16. A state mental hospital was difficult to comprehend.

Liz has had access to a number of computers and software packages that have helped her continue learning. She has used *Project Star*, an adult literacy program, to increase her reading vocabulary. She also has had access to games that improved her hand-eye coordination. She has needed relatively few adaptations since her disability affects her interpretation rather than physical access.

Liz's spelling skills have improved tremendously through the use of software packages such as *Wheel of Fortune* that combine spelling with a game format. Liz has also learned enough about computer operations to help her teachers overcome any intimidation caused by computers. After watching Liz boot up the computers at SpeciaLink, the ATA center in Covington, Ky., the teachers were not as scared of the technology. Liz also works with youngsters who come to the center.

The computers she uses are "off-the-shelf." The software is also mainly off-the-shelf, with a few other pieces developed by Liz's mother to help her develop computer and academic skills.

Liz's disability has caused her to be slower at learning new things, but using computers has enhanced her learning, helped her develop social skills and certainly increased her self-esteem and self-confidence.

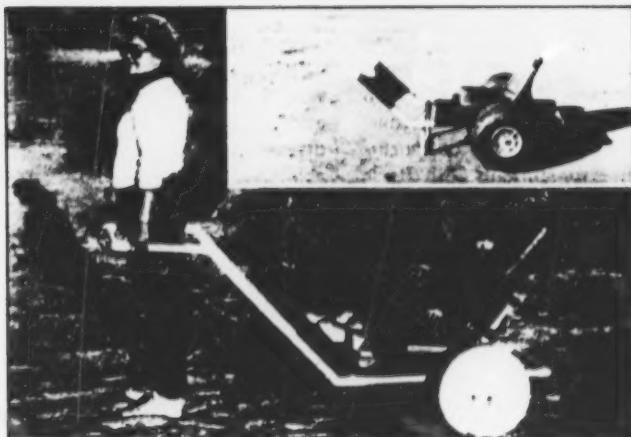
Liz is continuing to learn, despite the fact that she was supposed to stop 10 years ago.

Project Star is available from Hartley Courseware, 133 Bridge St., Dimondale, MI 48821, (800) 247-1380, (517) 646-6458, (517) 646-8451 (fax).

The Alliance for Technology Access (ATA) is a network of community-based technology resource centers dedicated to providing access to the assistive technologies and related services that enable people with disabilities to achieve productivity, independence and success according to their individual needs and interests.

ATA centers serve people of all ages with disabilities of all kinds and have comprehensive, multifaceted programs that reflect their specific community needs, as well as local talents and resources.

For more information about the ATA and the center nearest you, call (800) 992-8111 or (510) 528-0747.



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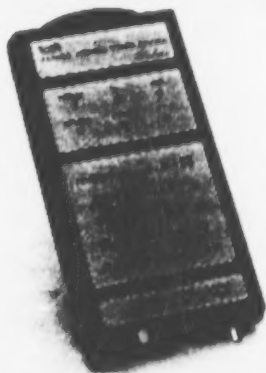
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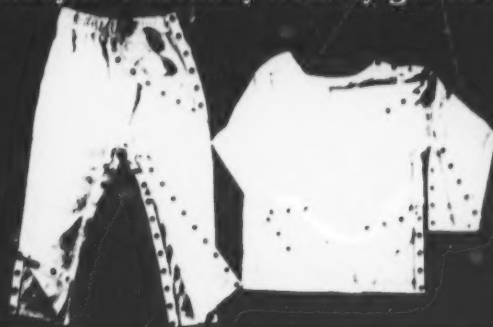
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The Resource Unit for Information and Education (RU) is a clearinghouse for information on prosthetics and orthotics (developing and fitting devices that activate or supplement a weakened or atrophied limb).

Information is available to consumers, service and research professionals, manufacturers and others. RU provides a 24-hour help line at (312) 908-6524. General information packets are available free of charge and other materials include laboratory publications such as the newsletter *Capabilities*, informational brochures and reports.

For more information, contact Else Tennessen, M.S., at the Resource Unit for Information and Education, Northwestern University Rehabilitation Engineering Program, 345 E. Superior St., Room 1441, Chicago, Ill. 60611, (312) 908-6524.

Education of Students with PKU Published

The National Institute of Child Health and Human Development (NICHD) has published a booklet called *Education of Students with Phenylketonuria*.

Phenylketonuria (PKU) is a hereditary abnormality that prevents the proper metabolism of the essential amino acid phenylalanine found in all protein foods.

With proper dietary control, people with PKU can live normal lives. If phenylalanine consumption is unrestricted or controlled too late, mild-to-severe mental retardation may result. While dietary control may be relatively easy to maintain when the child is at

home, it may become more difficult once he or she starts school. This booklet will help guide teachers, administrators and other personnel who work with children with PKU.

Free copies are available from the NICHD, 9000 Rockville Pike, Building 31, Room 2A32, Rockville, Md. 20892, (301) 496-5133.

Children May Benefit from New SSI Rule

Children with disabilities may receive higher Supplemental Security Income (SSI) benefits as a result of the new method the Social Security administration uses to compute the effect of parents' income on benefit payments.

The rule, which became effective Nov. 1, 1992, eliminates two of the three formulas previously used to determine how income will affect a child's eligibility for SSI and the amount of the benefit payment.

Parents of two groups of children are encouraged to contact Social Security to see if the new rule affects their eligibility: children whose applications for SSI benefits were filed before November 1992 and who were denied benefits based on their parents' income; and children for whom no application was filed because it was believed their parents' income would make them ineligible.

The SSI program provides monthly benefits to children who meet Social Security's definition of disability as well as other income requirements.

To find out more about the new rule or to obtain information about SSI for children, call Social Security's toll-free number, (800) 772-1213, business days between 7 a.m. and 7 p.m. (EST).

Financial Aid Paper Explains Process, Answers Questions

The HEATH Resource Center, a clearinghouse on postsecondary education for

people with disabilities, has a resource paper with information on financial aid opportunities for students with disabilities.

The paper, *1993 Financial Aid for Students with Disabilities*, discusses various types of aid, the jargon of financial aid and explains the process of obtaining aid. Issues of disability-related expenses and how these expenses can be met are also discussed in the paper as well as brief descriptions of vocational rehabilitation agencies.

1993 Financial Aid for Students with Disabilities is available free of charge from the HEATH Resource Center, 1 DuPont Cir., Suite 800, Washington, D.C. 20036, (800) 544-3284, (202) 939-9320.



Scientists Isolate Gene Believed to Cause ALD

The National Institute of Child Health and Human Development (NICHD) has announced that scientists supported by the Institute have located the gene that codes for adrenoleukodystrophy (ALD).

ALD is a genetic disease that is characterized by the progressive deterioration of cells in the central nervous system. This significant finding may pave the way to test the possibility of gene therapy for ALD.

ALD is passed on by females but affects only males. The disease affects approximately one out of every 20,000 males. It causes the breakdown of a fatty substance, known as myelin, that forms a barrier around nerve fibers.

The movie *Lorenzo's Oil*, an account of one family's search for a cure for their son with ALD, recently focused public attention on the disease. But while *Lorenzo's oil* may be beneficial to certain patients

with ALD, it does not seem to affect more severe forms of the disease and is not a cure.

Documentary About Learning Disability Wins Academy Award

Educating Peter, the story of a student with Down syndrome, recently received an Academy Award in the short documentary category. The program, which will air May 12 at 9:30 p.m. (EST) on HBO, is the story of Peter Gwazdauskas's first year mainstreamed in a regular classroom.

The documentary is about the changes that occur during the course of the school year as Peter, his classmates and their teacher learn lessons that go beyond their academic subjects. After many tribulations and a great deal of planning, they begin to accept, trust and learn from each other.

Educating Peter was produced and directed by Thomas C. Goodwin and Gerardine Wurzburg.

For more information, contact Direct Cinema Limited, P.O. Box 10003, Santa Monica, Calif. 90410-9003, (800) 525-0000.

ORGANIZATION NEWS

New Newsletter

- **VHL (von Hippel-Lindau syndrome) Family Forum**, 171 Clinton Rd., Brookline, MA 02146, (617) 232-5946 (evenings), (617) 734-8233 (fax).

New Support Groups

- **Myeloproliferative Disease Patient Network and Support Group (MPD)**, M.P.D. Research Ctr., 2220 Tiemann Ave., Baychester, NY 10469, (212) 231-0270.

- **Pull-thru Network**, for families with children born with anorectal malformations, 1 Circle Rd., Darien, CT 06820, (203) 655-6288; 62 Edgewood Ave., Wyckoff, NJ 07481, (201) 891-5977.

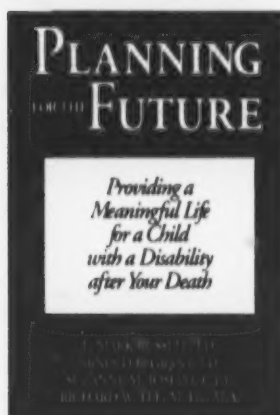
- **VHL (von Hippel-Lindau syndrome) Family Alliance**, 171 Clinton Rd., Brookline, MA 02146, (617) 232-5946 (evenings), (617) 734-8233 (fax).

CHARLES C THOMAS • PUBLISHER

- ☐ Jones, Carroll J.—**CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '93, 256 pp. (7 × 10), about \$45.75.
- ☐ Vaughan, C. Edwin—**THE STRUGGLE OF BLIND PEOPLE FOR SELF-DETERMINATION: The Dependency-Rehabilitation Conflict; Empowerment in the Blindness Community.** '93, 236 pp. (7 × 10), 3 il., about \$42.75.
- ☐ Jones, Carroll J.—**CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS.** '93, 174 pp. (7 × 10), \$36.75.
- ☐ Rakow, Sue F. V. & Carol E. Carpenter—**SIGNS OF SHARING: An Elementary Sign Language and Sex Awareness Curriculum.** '93, 300 pp. (8½ × 11), 245 il., about \$45.75.
- ☐ Jones, Carroll J.—**ENHANCING SELF-CONCEPTS AND ACHIEVEMENT OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 294 pp. (7 × 10), 7 tables, \$50.50.
- ☐ Irons-Reavis, Donna—**EDUCATIONAL INTERVENTION FOR THE STUDENT WITH MULTIPLE DISABILITIES.** '92, 140 pp. (7 × 10), 31 il., \$30.75.
- ☐ Jones, Carroll J.—**SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '92, 218 pp. (7 × 10), \$37.75.
- ☐ Cipani, Ennio—**A GUIDE TO DEVELOPING LANGUAGE COMPETENCE IN PRESCHOOL CHILDREN WITH SEVERE AND MODERATE HANDICAPS.** '91, 268 pp. (7 × 10), 6 il., 22 tables, \$52.75.
- ☐ Reavis, Donna—**ASSESSING STUDENTS WITH MULTIPLE DISABILITIES: Practical Guidelines for Practitioners.** '90, 110 pp. (7 × 10), 13 il., \$27.25.
- ☐ Prickett, Hugh T. & Earlene Duncan—**COPING WITH THE MULTI-HANDICAPPED HEARING IMPAIRED: A Practical Approach.** '88, 90 pp. (7 × 10), 2 tables, \$26.50.
- ☐ Rose, Harriet Wallace—**SOMETHING'S WRONG WITH MY CHILD! A Straightforward Presentation to Help Professionals and Parents to Better Understand Themselves in Dealing With the Emotionally-Charged Subject of Disabled Children.** '87, 210 pp. (7 × 10), \$35.75.
- ☐ Hulit, Lloyd M.—**STUTTERING: IN PERSPECTIVE: Practical Advice for Those Who Must Deal with Stuttering, for Adult Stutterers and Parents of Young Stutterers.** '85, 152 pp., \$29.25.
- ☐ Shearer, William M.—**ILLUSTRATED SPEECH ANATOMY.** (3rd Ed.) '79, 152 pp. (6¾ × 9¾), 91 il., \$31.25.
- ☐ Oppenheim, Rosalind C.—**EFFECTIVE TEACHING METHODS FOR AUTISTIC CHILDREN.** (2nd Ptg.) '77, 124 pp., \$26.00.
- ☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 300 pp. (7 × 10), 32 il., 8 tables, about \$54.00.
- ☐ Clark, Lynne W.—**FACULTY AND STUDENT CHALLENGES IN FACING CULTURAL AND LINGUISTIC DIVERSITY.** '93, 290 pp. (7 × 10), 6 il., 10 tables, about \$52.00.
- ☐ Lombana, Judy H.—**GUIDANCE FOR STUDENTS WITH DISABILITIES, 2nd Ed.** '92, 198 pp. (7 × 10), 1 table, \$45.75.
- ☐ Durán, Elva—**VOCATIONAL TRAINING AND EMPLOYMENT OF THE MODERATELY AND SEVERELY HANDICAPPED AND AUTISTIC ADOLESCENT WITH PARTICULAR EMPHASIS TO BILINGUAL SPECIAL EDUCATION.** '92, 182 pp. (7 × 10), 21 il., \$37.75.
- ☐ Jones, Carroll J.—**CASE STUDIES OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 236 pp. (7 × 10), \$47.75.
- ☐ Williams, Nancy S., & Sr. Maureen Brogan—**DEVELOPING LITERACY IN AT-RISK READERS: Using Literature in Clinic and Classroom.** '91, 170 pp. (7 × 10), 37 il., \$36.25.
- ☐ Rotatori, Anthony F., Robert A. Fox, David Sexton and James Miller—**COMPREHENSIVE ASSESSMENT IN SPECIAL EDUCATION: Approaches, Procedures and Concerns.** '90, 578 pp. (7 × 10), 22 il., \$97.75.
- ☐ Davis, Kimberly—**ADAPTED PHYSICAL EDUCATION FOR STUDENTS WITH AUTISM.** '90, 142 pp. (7 × 10), 10 il., \$32.75.
- ☐ Maloff, Chalda & Susan Macduff Wood—**BUSINESS AND SOCIAL ETIQUETTE WITH DISABLED PEOPLE: A Guide to Getting Along With Persons Who Have Impairments of Mobility, Vision, Hearing, or Speech.** '88, 162 pp. (7 × 10), \$37.00.
- ☐ Durán, Elva—**TEACHING THE MODERATELY AND SEVERELY HANDICAPPED STUDENT AND AUTISTIC ADOLESCENT: With Particular Attention to Bilingual Special Education.** '88, 250 pp. (7 × 10), 5 il., 3 tables, \$45.50.
- ☐ Golden, Larry B. & Dave Capuzzi—**HELPING FAMILIES HELP CHILDREN: Family Interventions with School-Related Problems.** '86, 276 pp. (7 × 10), 1 il., 2 tables, \$44.00.
- ☐ Geist, Chrisann Schiro & William A. Calzaretta—**PLACEMENT HANDBOOK FOR COUNSELING DISABLED PERSONS.** '82, 346 pp., 39 il., 1 table, \$55.50.
- ☐ Ross, Deborah & Sara Spencer—**READING AND WRITING TASK HIERARCHY.** '81, 350 pp. (8½ × 11), 21 il., \$48.50, spiral (paper).

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PLANNING FOR THE FUTURE

Providing a Meaningful Life for a Child with a Disability After Your Death

by L. Mark Russell, J.D., Arnold E. Grant, J.D., Suzanne M. Joseph, C.F.D. and Richard W. Fee, M.Ed., M.A.
©1993. Published by American Publishing Company, Evanston, Ill. To order: Exceptional Parent, 1170 Commonwealth Ave., Boston, MA 02134, (800) 742-4403, \$24.95 + \$3.50, shipping & handling.

The following excerpt from the Introduction has been reprinted with permission from the author.

When we first sat down to write this book, we thought about the many elements that we consider essential to a comprehensive estate plan where a person with a disability is involved. We thought about the importance of developing a life plan for your child and the importance of communicating that plan to future caregivers in order to provide continuity of care after you are gone. We thought about the importance of a financial plan and the difficulties inherent in providing for the lifetime needs of a person with a disability. We thought about the various legal documents involved — trusts, wills, and powers of attorney — that will enable you to leave property to your child in a form that will permit proper management, while at the same time not imperiling your child's

eligibility under government benefit programs that can be so vital. We thought about estate-tax planning, probate avoidance, and the protection of assets from the devastating costs of old age.

All of these items are important, and the major goal of a comprehensive estate plan is to deal with each of them. Omission of any one of these crucial elements from your estate plan could jeopardize your child's security...

Estate planning for families with a member who has a disability is different from other types of estate planning, because there is so much more that has to be done. Our goal is to convince you that estate planning is *essential* for every family and not an activity *only* for the wealthy. Parents must plan their estates, regardless of size, to secure the continued care and well-being of their child. Future caregivers must be selected, living arrangements investigated, and alternatives discussed. Families with limited financial resources must learn to maximize government benefits so that their child's financial needs will be satisfied.

...Many of these government benefits are unavailable to people who have more than an insignificant amount of property... You can leave property to your child in trusts that will provide for effective management and supplement government benefits, without affecting your child's eligibility for such benefits or subjecting the inheritance to government seizure under a cost-of-care claim. In fact, in many cases avoidance of government cost-of-care claims and maintenance of eligibility for government benefits are among the most important goals of an estate plan...

Although there are many alternatives that all parents with children who have disabilities should consider, there is no single magic formula for creating the appropriate estate plan. Every estate plan should be custom-fit to the family's circumstances and the needs of its members. The size of a family's estate affects

the need for estate-tax planning and the importance of government benefits. The nature and degree of your child's disability will help determine the type of living arrangement that will be appropriate. The ages of your children — both those with disabilities and those without — affect your need for insurance. The size of your family might influence the distribution of property. The age and maturity of children without disabilities will determine whether you will need trusts for them, as well as for the child with the disability. In other words, estate planning is a process of weighing numerous alternatives and making decisions that you hope will improve and secure your child's life now and in the future.

The task is daunting, but it is achievable. We have helped many clients who have children with disabilities develop effective estate plans. Our book is intended to be a guide to effective decision making for parents who have children with disabilities. It explains the estate-planning process in an understandable, comprehensive way and provides methods of integrating the planning for children who have disabilities within the estate-planning process in general...

Laws and requirements about estate-planning methods are changing constantly. It is therefore necessary to check all your plans closely with a knowledgeable attorney before they become final. Once a plan is prepared, it should be periodically evaluated and revised to guarantee the maximum possible care for your child in light of changes in his or her life and changes in your financial situation.

Although there can be no guarantee that an estate plan will provide lifelong care and protection for your child, a plan is essential for parents who are concerned about what will happen to their children after they are gone. With a proper estate plan, parents can avoid a drastic interruption in care and do everything that is possible to ensure that their child will have a comfortable and fulfilling life.

MEDIA BUYERS' GUIDE

KEY: ➤ Books for Children ➤ Books for Parents & Professionals
 + Educational Materials ▼ Videotapes ⊕ Audiotapes

➤ **Turtle Books:** for children with disabilities and their friends. Write for free descriptive brochure. Also ask for free brochure "Tips for Selecting Books for Children with Disabilities" for your favorite librarian. **Jason & Nordic Publ.**, P.O. Box 441, Hollidaysburg, PA 16648.

➤ **Charlie's Chuckle** by Clara Berkus. A children's book about a boy with Down syndrome who becomes the local hero when his infectious laugh brings harmony to his home town. **\$14.95** (+\$3.50). **Woodbine House**, 5615 Fishers Ln., Rockville, MD 20852, (800) 843-7323.

➤ **Planning for the Future.** A newly published 400 page book provides parents of a child with a disability with comprehensive information on life and estate planning. **\$24.95** (+\$3.50 s&h). **American Publishing Co.**, P.O. Box 988, Evanston, IL 60204-0988, (800) 247-6553.

➤ **Lifepoints Magazine.** A career, sports and leisure information resource written by visually impaired role models. Published quarterly in braille, large print and on 4-track cassette. **\$15/year**. **Blindskills, Inc.**, P.O. Box 5181, Salem, OR 97304.

➤ **Friends in the Park.** (ages 3-8), full-color photos feature children with and without disabilities playing together. **\$7.95** (+\$2 s&h); **We Can Do It!** (ages 3-8), full-color photos show daily events in the lives of five special children. **\$7.95** (+\$2 s&h); **Animal Signs and Word Signs.** (ages 1-4), an introduction to Sign Language with full-color photos of animals and everyday objects. **\$4.95** (+\$2 s&h); **Where's the Puppy? & What Happens Next?** (1-4), these lift-the-flap books include photos of children with Down syndrome. **\$4.95** (+\$2 s&h). **Checkerboard Press, Inc.**, 30 Vesey Street, New York, New York, 10007.

➤ **"Reaching Out"** Bi-monthly newsletter providing articles about raising children with CdLS. Features information contributed by families and professionals, including a medical column. **Cornelia de Lange Syndrome**, 60 Dyer Ave., Collinsville, CT 06022-1273.

➤ **The Sibling Support Group Manual.** 150+ pgs. on how to organize and run sibling support groups. Planning, discussion, publicity, games, resources, prog. evaluation. **\$17.50** (+\$3 s&h). **Easter Seal's Sibling Project**, 632 Fort Duquesne Blvd., Pittsburgh, PA 15222, (412) 281-7244.

➤ **The Complete Directory for People with Learning Disabilities.** Full database in print form of 8,000 programs, products, associations, support groups, newsletters, computers, curriculum & assessment materials. **\$99** (incl. s&h). **Grey House Publ.**, Pocket Knife Sq., Lakeville, CT 06039.

➤ **Music For Little People.** Don't let the title fool you! Free mail order catalog offers much more than children's music! Carefully chosen, multi-cultural, socially responsible audio, video, musical instruments, books, toys, games and clothing. Call (800) 727-2233.

➤ **Pediatric Emergencies, Vol. 1.** Powerful new video featuring real emergency physicians and field paramedics. Instructs parents about safety and what to do if their child ever has a life-threatening accident. **\$39.95** (+\$3 s&h). **Carolina Video**, call (800) 322-0123. VISA, MC, AE.

➤ **FREE — The NEW Special Needs Project Book Catalog.** Unique selection of the best books from all publishers about disabilities. Comprehensive resource for parents, children & prof. **Special Needs Project**, 1482 E. Valley Rd., #A121, Santa Barbara, CA 93108, (800) 333-6867.

➤ **Free Book Catalog: The 1992 Special Needs Catalog** features a collection of valuable books for children with disabilities and their parents on Down syndrome, CP, autism, spec. ed. and more. Contact **Woodbine House**, 5615 Fishers Ln., Rockville, MD 20852, (800) 843-7323.

➤ **Taking Charge: Teenagers Talk about Life & Physical Disabilities,** by Kriegsman, et al. A book written for and in consultation with teens with physical disabilities. Discusses self-esteem, relationships, and goals. **Woodbine House**, 5615 Fishers Ln., Rockville, MD 20852, (800) 843-7323.

▼ **DAY BY DAY: Raising the Child with Autism/PDD** by Joan F. Goodman & Susan Hoban. 60-min. videotape on daily coping skills & strategies for parents of children with PDD. **\$150** (+\$3.50 s&h); special for parents: **\$29.95** (+\$3.50 s&h). **Guilford Publ.**, 72 Spring St., NY, NY 10012, (800) 365-7006.

▼ **AROUND THE CLOCK: Parenting the Delayed ADD Child** by Joan F. Goodman & Susan Hoban. 30-min., covering such topics as symptoms, coping, & acceptance of ADD. **\$150** (\$3.50 s&h); special for parents: **\$29.95** (3.50 s&h). **Guilford Publ.**, 72 Spring St., NY, NY 10012, (800) 365-7006.

▼ **Interax Video Sign Language Course.** Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. **Free brochure.** **\$199** (+\$4.50 s&h). **Interax Training, Inc.**, P.O. Box 473106, Garland, TX 75047-3106, (800) 242-5583.

▼ **"Say It With Sign"** Video library on signing. Drs. Larry & Sharon Solow teach you to sign with ASL & fingerspelling. 1st tape **\$9.95** w/subscription. Receive addtl. 2-hr video each mo. at \$29.95 ea. Cancel sub. anytime. Free catalog; credit card orders. **Valiant Ed. Videos**, (800) 266-2159.

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Wichita, KS 67219
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Massachusetts

Berkshire Children's Community, 249 N. Plain Rd.
Housatonic, MA 01236
(413) 528-2523

For children who are severely retarded, multiply disabled. Private, nonprofit, residential school located in the Berkshires.

Cardinal Cushing School
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Hanover, MA 02333
(617) 826-5371

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Cotting School
453 Concord Avenue
Lexington, MA 02173
(617) 262-7323

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Assonet, MA 02702
(508) 644-3101, Ext. 328

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The Kolburne School, Inc.
Southfield Road
New Marlborough, MA 01230
(413) 229-8787

A coed Residential Treatment Ctr. providing a safe, structured, warm, therapeutic environment for students ages 8-24. JCAHO accredited.

League School of Boston, Inc.
225 Nevada St.
Newtonville, MA 02160
(617) 964-3260

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New England Villages, Inc.
664 EP School Street
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(617) 293-5461

Private residential community for adults with developmental disabilities. Vocational, recreational programs.

Riverbrook
108 Ice Glen Road
Stockbridge, MA 01230
(413) 298-4926

Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015

Day/residential school for children with develop. disabilities, behavior disorders age 3-22. Integrated preschool, inclusion svcs., staff intensive prog., functional activity based curr., supported employment in modern school and group homes.

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Austin, MN 55912
(507) 433-7301

For the needs of Supported Living Arrangements, ICF/MR's, and Waivered Programs, Woodvale has created low-cost, portable assessment systems and curriculum guides for the following areas: Sexuality, Nutritional Needs, Independent Skills, Personal Strengths & Needs.

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Greenfield, NH 03047
(603) 547-3311

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Riverbrook
108 Ice Glen Road
Stockbridge, MA 01230
(413) 298-4926
Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

New Jersey

The Devereux Foundation
Contact: Nat'l Referral Services
(800) 345-1292, x3045 or
(215) 964-3045

In residential, day, and community-based treatment centers nationwide, Devereux provides comprehensive services to indiv. of all ages who have: emotional disturbances, develop. disab., mental retardation, dual diagnosis, autism, post-head trauma. Please call for more information!

New York

Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

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Edmeston, NY 13335
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Riverbrook
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Stockbridge, MA 01230
(413) 298-4926

Res. facility for 22 moderately mentally handicapped women, prog. emphasizes self care, social, rec. & voc. skills. No upper age limit.

North Carolina

Irene Wortham Ctr., Inc.
P.O. Box 5655
Asheville, NC 28813
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Developmental Day School (0-21)
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Adult Day Activity Center (18+)
Providing rehabilitation services for mentally and physically handicapped, as well as medically fragile. Please call or write for more information.

continued on page 56

The New England Center for Autism is dedicated to providing the most caring, comprehensive, and innovative education

available today to children with autism and mental retardation.

Children of Promise



"I want to thank The Center's staff for the foresight, persistence and expertise in executing perhaps the finest program for autistic children and adults in the nation."

*Barbara C. Frey
parent*

Our behaviorally oriented, community-based center, serving students aged 3 to adult, has revolutionized the way in which children with autism and developmental disabilities are cared for and educated. At admission, these students have severe behavioral problems including aggression, self-injurious behavior and hyperactivity. Half of our students have seizure disorders.

Our educational facility is located in

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*For more information, please contact
Vincent Strully, Jr., Executive Director.*

The New England Center for Autism, Inc.

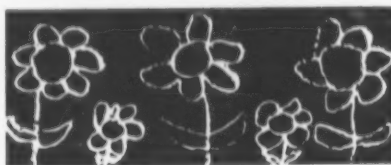
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Each person is a unique individual with God-given potential to live a personally satisfying, productive life. At St. Coletta's, we not only believe this, but we act on our belief. Each of our students and adult residents receives the kind of personal attention they might expect to receive from their own family. Their education, home life, recreation and leisure activities, vocational training and employment are planned to make the most of their individual interests and abilities. We are a caring community where each of us shares a loving concern for one another. In a world where love is sometimes in short supply, we have it in abundance.

St. Coletta School, founded in 1904, offers a year-round academic residential program for children and young adults (ages 6-25) with mental retardation. Special services include personal and vocational counseling, socialization skills,

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Where Love
Is Sometimes In
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**We Have
It In
Abundance**



St. Coletta School

W4955 Highway 18
Jefferson, Wisconsin 53549

personal living skills, transitional home living, speech and language development, music and art, adaptive physical education and swimming, and physical and occupational therapy.

Our Alverno ICF/MR program provides superior quality care for adult residents in a pleasant, attractive setting. Wholesome meals, attentive staff, and stimulating activities are among the things which make Alverno of special interest to families seeking comprehensive care.

Other St. Coletta programs include habilitation/vocational training, employment opportunities for adult workers, and community transitional group homes. For further information, contact the Admissions Office at (414) 674-4330.

SCHOOLS, CAMPS & RESIDENCES DIRECTORY

North Dakota

Anne Carlsen School
301 Seventh Avenue, NW
Jamestown, ND 58401
(701) 252-3850

Here young people with disabilities can achieve their highest potential. Many programs for intensive evaluation and intervention.

Ohio

St. John's Villa
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615
(216) 627-9789

Private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. Located in the hills of northeastern Ohio. Please call for more information.

Pennsylvania

H.M.S. School for Children with CP, 4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566

Residential/day school prog. for children 2-21 who are severely physically disabled by CP. Integrated therapies. Assistive tech.

Keystone City Residence
406 N. Washington Avenue
Scranton, PA 18503
(717) 346-7561 Mr. Fleese

Community homes, urban & rural, located in NE, PA, Pocono Mtns., NJ. Avail. to child. & adults with dev. dis. Summer camp with arts feature, voc. and work placement and full prof. & support services. Prader-Willi prog. Reasonable fees & highly regarded program. Fully licensed.

Martha Lloyd Community Services
190 W. Main Street
Troy, PA 16947-1199
(717) 297-2185

A private residential program for ambulatory mentally retarded women, ages 15 and older. Emphasis on vocational and community life skills training. Home-like community residence in north central Pennsylvania.

Woods Services

Langhorne, PA 19047
(800) 782-3646

Founded in 1913 as The Woods Schools, a private, non-profit organization, serves children and adults with develop. disab., challenging behaviors, medical complexities, traumatic brain injury, neurological disorders, dual-diagnosis, Prader-Willi & Rett Syndromes. Res., educ., health, voc., rec., therap. svcs. avail.

South Dakota

Crippled Children's Hospital and School
2501 West 26th Street
Sioux Falls, SD 57105
(605) 336-1840

Private, nonprofit school and residence for children aged 0-21 with physical and developmental disabilities. Family centered services are provided by a multidisciplinary team based on each child's needs. Day services are available.

Virginia

Faith Mission Home
HCR 1, Box 114
Free Union, VA 22940
(804) 985-2294

Loving, residential training center for ambulatory children and young adults with mental disabilities. Please call for more information.

Wisconsin

Chileda Habilitation Institute
1020 Mississippi St.
LaCrosse, WI 54601
(608) 782-6480

Res. treatment ctr. training & intensive therapy for children w/ severe mental & physical disabilities.

St. Coletta School
W4955 Highway 18
Jefferson, WI 53549
(414) 674-4330

Year-round res. prog. in academic instruction & prevocational training for MR/DD. Adult res. facility w/ work opp. for aging MR/DD.

Exceptional Parent

Back Issues!

QTY.	ISSUE	FEATURES	TOTAL
	July/Aug 1992	"Mini" Comm. Boards; Incontinence; A Flag-Flying 4th; Augmentative Comm.	
	March 1992	3rd Annual Mobility Guide; Wheelchair Maintenance; Children & the ADA; Van Lifts;	
	Nov/Dec 1991	9th Annual Computer Technology Issue; Parenting Your Child Without Disabilities.	
	Oct/Nov 1991	Is Your Child Being Humiliated? Car Seat Safety; Tips for Parents; 800# Directory.	
	September 1991	19th Annual Education Issue; School Bus Safety; Schools, Ins. & Your Family's Financial Security.	
	July/Aug 1991	Corporate Award — McDonald's; One Mother's Quest for Normalcy; Bathroom Accessibility.	
	June 1991	Summer Program Winners; Mainstreaming; Social Security Can Help; Seating & Positioning.	
	Nov/Dec 1990	8th Annual Technology Issue; Annual Income Tax Guide; 1990 Best Tech. & Everyday Life Awards.	
	October 1990	Parent to Parent National Survey; Adaptable Playgrounds; Finding the Right Software.	
	July/Aug 1990	Teaching About Sexuality; Preparing for Surgery; Aquatic Activities.	
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A-M 93



Berkshire Meadows - a place of "small miracles"

Hot water swirls and churns, limbs relax, movement eases. A child smiles. Soothed and buoyed by the bubbling warmth, he responds as his arms and legs are gently stretched, pushing against the flow of the water, relaxing back with it, each movement broader, smoother than the last.



Young bodies float in a broad expanse of bath-tub-warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex; laughter at splashes and water-antics; shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

The little boy described above does not wear a daytime brace to maintain his range of movement. Instead, once a week, he experiences the intense relaxation of the Hubbard tank. Kept at a water-temperature of 98 to 102 degrees, the butterfly shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more coordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young man in the therapeutic pool will also experience a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a movable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the children, when in the pool, to move in ways in which otherwise they cannot: if they cannot walk on land owing to poor strength or joint pain, they might be able to walk independently when in the water, or they might acquire real movement, instead of spasticity. Here, in the pool's supportive warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced - and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multi-faceted program at Berkshire Meadows, a private, non-profit residential school for children and adolescents who are developmentally delayed and multiply disabled. Nestled in the heart of the Berkshire Hills, the attractive and carefully-designed campus also houses several cheerful residences and a Learning Center equipped with state-of-the-art teaching aids. The program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of pre-cognitive, cognitive, pre-vocational and independent living skills. There is an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.

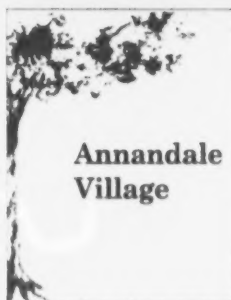


At Berkshire Meadows we believe that all children, no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

For further information, please contact: Ms. Gail Charpentier, Berkshire Meadows,
249 North Plain Road, Housatonic, MA 01236 (413) 528-2523



SCHOOLS, CAMPS & RESIDENCES GUIDE



"THEIR COMMUNITY ... WITH OUR HELP" Private, nonprofit community for adults with developmental disabilities offering residential/ non-residential transitional programs and services.

- Job Training • Arts Activities.
- Therapeutic recreation.
- Case management.
- Founded 1969.
- 125-acre wooded environment.

Contact: **Annandale at Suwanee, Inc.**
3500 Annandale Lane, Box 7
Suwanee, GA 30174
(404) 945-8381



INDIVIDUAL DAY & RESIDENTIAL PROGRAMS for children and adults with special needs including dev. disabilities, autism, head injury.

- A continuum of educational, vocational, & community living options.
- Complete clinical support services.
- Outpatient evaluation and remediation services.
- Neuropsychological testing.
- Vacation opportunities.

Contact: **Bancroft**
Hopkins Lane
Haddonfield, NJ 08033
(609) 429-0010 ext. 347



DID I HEAR YOU SAY HELP?

- Are you looking for appropriate services for yourself, your family member or client?
- Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

Then call our toll-free hotline:
(800) 369-INFO.

Contact: **A.L. Napolitano**
Bethesda Lutheran Homes & Services
700 Hoffman Drive
Watertown, WI 53094
(800) 369-INFO



THE DUVALL HOME, EST. 1945.
A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory people with mental retardation of all ages:

- 24-hour nursing care.
- Lovely 24-acre rural campus.
- Recreational and training activities.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 36
Glenwood, FL 32722
(904) 734-2874



"MAXIMIZING INDIVIDUAL POTENTIAL"

- Community-based, private day/ residential treatment.
- Positive behavioral management.
- Ages 8-22, multiple disabilities, mentally retarded, behavior disordered, autistic & hearing impaired.
- 12-month program.
- 10 miles west of Boston.

Contact: Student Services Coordinator
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000



RIVERBROOK

A private residential facility designed to meet the needs of women who are moderately mentally retarded. The gracious estate houses 21 clients in a warm, family atmosphere.

Contact: Barbara Pastie
Riverbrook
Ice Glen Road
Stockbridge, MA 01262
(413) 298-4926



CARDINAL CUSHING SCHOOL & TRAINING CTR. Residential, academic and vocational services for students with all levels of developmental delays, including Prader-Willi Synd. Ages 6-22. 766 Approved. 400 Washington St., Hanover, MA 02339 (617) 826-6371

BRAINTREE ST. COLETTA DAY SCHOOL Functional daily living skills, practical academics, pre-voc. prog. for students with severe developmental disabilities, mult. disabilities and autistic behaviors. Ages 3-22. 766 Appr. 85 Washington St., Braintree, MA 02184 (617) 848-6250.



TALL PINE CAMP. Co-ed mountain camping for children and adults with MR. Programs and activities based on individual abilities. Prof. staff, two full-time nurses. Self-care & social skills emphasized. Academics, incl. computer programming. Many recreational activities including: swimming, crafts, boating, equestrian prog., etc. 2, 3, 6 wk. sessions available for \$300/wk.

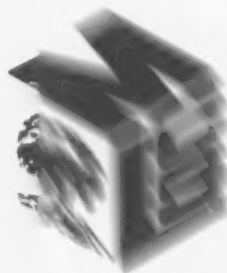
Contact: Ron & Cammie Eydt
Tall Pine Camp, Rt. 2, Box 194-A
Tellico Plains, TN 37385
(615) 261-2329



New Life Opportunities For Men

For more than sixty-five years, Martha Lloyd Community Services has offered superior quality day and residential services for women with developmental disabilities. Now, these opportunities are available to men as well in a newly established community home in Troy, Pennsylvania.

- Semi-independent living in a modern, attractive home. Training provided in home care and maintenance, budgeting, and household management.
- Life skills and vocational training in an established day program.
- Employment opportunities in the community and within the Martha Lloyd complex.
- Easy access to nearby community resources including shopping, restaurants, churches, and recreation.
- Unique leisure and recreational experience in a rural community setting including camping, fishing, hiking, and participation in activities at local parks and a nearby university.
- A caring professional staff experienced in working with individuals with developmental disabilities. Interdisciplinary team approach assures continuity and consistency in individual planning.
- Excellent health care provided by on-staff health professionals and a community medical center.
- Annual fees among the lowest in the nation.



**MARTHA
LLOYD
COMMUNITY
SERVICES**

**For Information Call
(717) 297-2185**

Or Write: Martha Lloyd Community Services
Troy, PA 18967

Anyone who has ever visited the "Learning School and Training Center and Training Center" (LSTC) will undoubtedly agree that the experience was inspirational. This is a program, supported by St. Collette's Hospital, that provides a unique educational experience for exceptional children and their families.

Established in 1967, the LSTC has been a pioneer in the field of exceptional children and their families.

The LSTC is a unique educational experience for exceptional children and their families. It is a program that provides a unique educational experience for exceptional children and their families.

At the LSTC, St. Collette's Day School, approximately 25 students ages 5-12 enjoy a state-of-the-art facility which enables instructors to provide a high degree of personal interaction from occupational education and behavioral management to the development of social and domestic skills. Activities enable students to gain the highest possible degree of independence. A residential component is also available.

Exceptional Schools

St. Collette's Day School



John W. Shyne, Jr., President
(617) 826-6371
Hanover, MA

Located in Hanover, the "Learning School and Training Center" provides a unique educational experience for exceptional children and their families. The program is supported by St. Collette's Hospital and provides a unique educational experience for exceptional children and their families.

The LSTC is a unique educational experience for exceptional children and their families. It is a program that provides a unique educational experience for exceptional children and their families.

Services include:
Peer With Program
Vocational Training
Independent Living Training
Adaptive Physical Therapy
Speech Therapy & Counseling
Community Skills & Summer Programs
Bi-Lingual (Spanish Program)



Is Everyone Focusing On The Negative?

It happens all too often to children with special needs.

At Corning School, we focus on your child. Building the skills he has. Helping him acquire new ones. And nurturing his self-esteem.

We can make opportunities for your child to shine. Contact us today.

Corning School, 1000 Main Street, Hanover, MA 01927

Phone: (617) 826-6371

Fax: (617) 826-6372

Website: www.corning-school.org

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Corning School

We focus on your child.

For boys and girls with learning, physical, communicable or medical needs.

455 Concord Avenue, Lexington, MA 02173

(617) 862-7525

What readers are saying about Exceptional Parent

"Exceptional Parent... is the finest publication of its kind... must reading for all those with a handicapped child. It could change their lives."

Ann Landers

"I highly recommend Exceptional Parent magazine to all parents of children with disabilities."

T. Berry Brazelton, M.D.

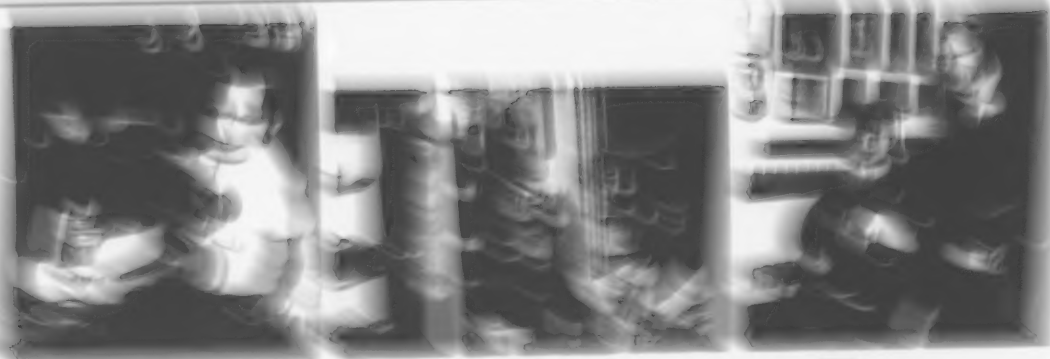
Clinical Professor of Pediatrics

Harvard Medical School

Author of Doctor and Child, On Becoming a Family,

What Every Baby Knows, Infants and Mothers,

Toddler and Parents



Our Services Are Barrier-Free

Persons with disabilities come to all ages. We serve people who are limited by physical or mental challenges. Anne Carlsen School serves persons throughout their lives. There are no age barriers.

Once, Anne Carlsen School was one of the few alternatives for young people with disabilities. Parents brought their children, often from great distances, for the education and therapies the school provided.

Many children stayed throughout their school years, growing into young adults who could live independent lives and make contributions to their families and society. They also spent many months of the year away from their families and home communities.

More recently, mainstreaming has brought services to the child. Today's parents, special educators and therapists know the value of a loving family and supportive friends and neighbors to children of all ages and abilities.

Today, Anne Carlsen School serves children for shorter stays. As always, we are committed to providing high quality individualized education and rehabilitation. We offer loving care and support to the students we serve as well as vocational training and assistive technology.

We work in cooperation with our student's local school system. We are committed to providing the best possible education and rehabilitation for each child. We may do a wonderful job of providing these

services, but sometimes we are not the best place for a child. At times, a student may move to the local school or need staff or technology, or because of the cost of the services, the child may require the type or amount of rehabilitation needed.

Anne Carlsen School augments services provided by the child's home school district. Through extensive diagnostic evaluation and therapy, we determine the child's specific needs and the rehabilitative answers to their challenges. Students no longer spend all their school years here. We diagnose their needs, recommend the therapy program and send them home with the tools needed for success at home and in school.

And, it doesn't stop there. A young child may come here for evaluations to help his parents to prepare for school. The same child, during the school years may outgrow a program, need updated technology, or want to try some different equipment. During and following high school, the young person may come here for help on daily living skills. Later, job training may be the focus of another short stay.

Anne Carlsen School is a resource center for people with disabilities of all ages. We are also a resource for the families of people with special needs. Do you want to know more about your child's needs? Do you want to ask about the impact of your child's special needs? Anne Carlsen School has people who can help you. We have people who can help your child's teacher with questions about technology.

Anne Carlsen School can help.
Call toll-free (800) 568-5175

301 Seventh Avenue, NW
Jamestown, North Dakota 58401



Anne Carlsen
School

Working together for a better future!



At Devereux, the concept of working together is emphasized and encouraged.

In residential, day, and community-based treatment centers nationwide, Devereux provides comprehensive services to individuals of all ages who have:

- Emotional disturbances
- Developmental disabilities
- Mental retardation
- Autism
- Anxiety disorders
- Depression
- Attention deficit disorder
- A wide range of therapeutic, educational, and vocational

programs tailored to the specific needs of the individual.

- Individual, group, and family therapies

Devereux programs:

- Residential centers
- Specialized programs in psychiatric hospitals/intensive residential treatment centers
- Community-based living

Devereux is:

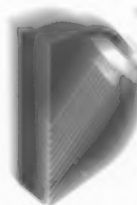
- A national organization with offices in Connecticut, Delaware, Florida, Georgia, Massachusetts, New Jersey, New York, and Texas.

Contact: National Referral Services

1-800-545-1292, X3045 or

215/964-3045

FAX: 215/971-4600



The
Devereux
Foundation

FAMILY SUPPORT

continued from page 11

undiagnosed. I felt the desperation of wondering, "What is the cause?" I want to help others develop an awareness of CDG so that if there is another undiagnosed person with the features of CDG, they will feel hope and know they are not alone.

P.F.S.
Wisconsin

Drama Programs for Children with Disabilities

I am the parent of a five-year-old autistic boy. Prior to his onset at the age of 19 months, I was working on my master's degree in theatre arts. I discontinued that pursuit but have now returned to finish my degree.

For my thesis, I have decided to combine the two loves of my life, my son and the theatre, by writing on the theatre and children with disabilities.

If you know of any programs where drama has benefitted children with autism (or children with any type of disability), I would love to hear from you. My goal is to make these programs available to our special children!

S.H.
California

Parents Search is an opportunity for our subscribers to get information from parents about their practical experience in handling the everyday problems of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Anyone who wishes to submit or reply to a letter in *Parents Search* or *Respond* should write to:

Exceptional Parent

1170 Commonwealth Ave., 3rd Floor
Boston, Mass. 02134-4646.

Please indicate whether it is a **search** or **response** letter and in which issue the original letter was printed when addressing a reply. All responses will be forwarded and may be published in our *Parents Respond* column.

For technical information about a disability, we encourage you to contact NORD (P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518) or refer to *The Annual Directory of National Organizations, 1992-93*, in the September 1992 issue of *Exceptional Parent* (available from the above address for \$6 including postage and handling).

When The World Starts Spinning



The people around him started spinning around and around in crazy circles. Jesse struggled desperately to find a familiar face among the swirling images, but everything looked distorted and strange. To Jesse, it felt like the whole world had turned upside-down. In reality, he was lost in a seizure.

For Jesse, seizures were an unavoidable part of living with multiple disorders. At times his reactions were so severe he would inflict bruises on himself. After years of searching for a place where their son could get the help he needed to learn and grow, Jesse's parents found Heartspring.

At Heartspring, seizure management plays an integral part in the individualized programs we develop for each child who experiences seizures. Every member of our staff who works with children is trained in seizure management. We strive to reduce the occurrences of seizures through a balance of diet, physical, occupational and behavioral therapy, and the reduction of medications to a minimum.

13 months after Jesse entered Heartspring, his seizures have been reduced from twice a day to less than once a month. He not only participates freely in class, but plays a tuba, and even enjoys riding a merry-go-round. His parents credit the Institute with the balance their son has found.

For more information on the individualized programs we provide for children who suffer from seizures, call Heartspring.



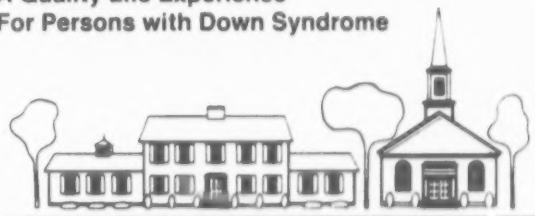
HEARTSPRING
A LIFESKILLS LEARNING CENTER

2400 JARDINE DRIVE WICHITA, KANSAS 67219-4699
316 262 8271 800 937 4644

FORMERLY THE INSTITUTE OF LOGOPEDICS

Pathfinder Village

**A Quality Life Experience
For Persons with Down Syndrome**



In this picturesque colonial village, located in scenic central New York State, life is full of wholesome activities and rewarding opportunities. Residents with Down Syndrome experience the joy and personal satisfaction of learning, working, and participating in a vital, dynamic community. Our year-round, co-ed program includes education, recreation, and employment opportunities plus the chance to live life to the fullest. *Call us today.*

**R.R. #1, Box 32-A, Edmeston, NY 13335
Telephone (607) 965-8377**

THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.



new england villages, inc.

**A Model, Supportive Community
For Mentally Retarded Adults**

664EP School Street, Pembroke, MA 02359 (617) 293-5461



Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615



Meeting the needs of children and adolescents with Challenging Behavior Disorders

The Center for Challenging Behaviors is a highly structured program designed for young people with mental retardation who exhibit behaviors such as self-injury, aggression, and property destruction. These behaviors often prevent their placement in less restrictive settings. The Center, located on the main campus of The Woods Schools, in suburban Philadelphia, opened in May 1992 and serves a maximum of 10 residents.

The Center offers an intensive therapeutic environment that combines the technologies of applied behavior analysis with the support of psychiatry. Individualized programs of positive behavior therapy are implemented in the residence, classrooms and specialized therapy sessions. No aversives are employed. The staff to client ratio is 1 to 2, and the availability and use of allied professional services and therapies exceeds traditional programs. For further information contact Dr. Scott Sprent, Administrator of Clinical Services.

The Center for Challenging Behaviors

Woods Services, Langhorne, Pennsylvania 19047

1-800-782-3646



Special Care for Special People

Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 600-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or
write for brochure

THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601

John P. Stewart, M.D., Resident Physician

Crystal Springs School



Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- Approved by the Massachusetts Department of Education as a special education resource.
- Licensed by the Massachusetts Office for Children.
- Serving severely and profoundly multiply handicapped children and young adults aged 3-22.
- 60 acre campus in Southeast Massachusetts, close to Boston, Cape Cod, Providence and Newport, R.I.

For information, Please Call:
Cheryl Andrade, Admissions Coordinator
(508) 644-5537

Providing Quality Services for Children and Adults
with Autism and Related Developmental Disabilities



Day Early Intervention Age 22
Residential Ages 6-22
Farmstead Age 18-Adulthood

Twelve-Month Day Educational Programming

Specialized Community Residences

Early Intervention and Home Training

Community Based Supportive Employment and Vocational Training

After-School Recreational Programs

Friendship Farms: Adult Farm Living in the Heart of Cranberry Country

League School of Boston, Inc.
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260

Herman T. Fishbein
Executive Director

Accreditation: Massachusetts Dept. of Education, Office for Children; Dept. of Social Services; Dept. of Mental Retardation; Dept. of Mental Health; NY Dept. of Education

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- **Physical Therapy**
- **Special Education**
- **Occupational Therapy**
- **Music Therapy**
- **Speech and Language Therapy**
- **Special Medical Attention**
- **Communication Aids**
- **Adapted Recreational Activities**

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215) 222-2566



continued from page 12

worry about normalization later. Our seven-year-old son, Patrick, had a reflux condition secondary to severe brain injury and required a gastrostomy and a funduplication. The following are some ideas that worked for our child:

- Seat the baby in a feeder seat or high chair at mealtime and allow the child to explore foods without any requirements of eating.

We started with squirts of whipped cream. Pat mainly smeared it on the tray and himself, but he did taste some of it when he brought his hands to his mouth. (This requires a high mess tolerance on the part of the parent.)

- Feed the child orally at the same time he or she is receiving a G-tube drip feeding. This will help the child associate a full tummy feeling with oral feedings.

- Try dipping the child's pacifier in something pleasant like bananas

or applesauce. You may need to use a small amount of food initially and build up at a slow pace.

- Introduce new tastes very gradually. Stick with what works and immediately discard what does not.

Pat still requires G-tube feedings and has limited swallowing abilities. Despite this, he sits with the family at mealtimes and plows through his oral foods with gusto. He can tolerate modified versions of most of the regular family fare.

E.S.K.
Ohio

Joubert Syndrome

A response to M.M.'s Parents Search, February 1993.

Our two-year-old daughter, Alyssa, has Joubert syndrome. This is a rare, genetically-transmitted disorder marked by partial or complete absence of the cerebellar vermis, abnormal breathing patterns (apnea and fast, puppy-like panting),

abnormal eye movements (commonly jerky eye movements and tracking problems), ataxia (characterized by over- and under-reaching, shakiness and a wide-based gait while walking) and sometimes mental delays. The vermis controls coordination and balance and the eye and breathing abnormalities originate from the brain stem.

We are part of the Joubert Syndrome Parents-In-Touch Network, a self-help network which offers a list of other families whose children are affected with Joubert syndrome and a wonderful newsletter which is published quarterly. (Joubert Syndrome Parents-In-Touch Network, 12348 Summer Meadow Rd., Rock, Mich. 49830, (906) 359-4707.)

We are also planning our first conference to be held July 31, 1993, at the Sheraton National Hotel in Arlington, Va.

M.V.
Michigan

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Going Bananas!

by Alice Wershing

Here is a game that lets players have a fast and frenzied fruit fight without the mess! *Monkey Mania™* from Parker Brothers involves two to four players, and the approximate playing time is three minutes per game. The rules are simple — the player whose monkey swallows the most bananas is the winner!

The game begins with the players saying "monkey, monkey, monkey" then pushing levers so their monkeys open their mouths and swallow the bananas as they move by. Pushing the levers also shakes more bananas out of the tree located in the center of the game. The players have to move quickly to shake the tree in their direction so their monkeys can swallow more bananas.

This game is easily modified to make activating the levers easier for some players. Cut two similar lengths of pipe insulation tubing, available from a hardware store, and place them around the ears of a monkey by cutting a slit up the seam of the tubing. The tubing will then extend above the head of the monkey to allow for a two-handed grip. If additional stability is needed, cut wooden dowel rods to length and insert them into the tubing. Use a hot glue gun to attach the rubber tubing to the ears of the monkey. The player can then use these additional handles to open his or her monkey's mouth and shake the tree.

A second option is to create a single handle that is larger than the lever provided. Cut a short length of pipe insulation with an additional hole in the

side of the tubing to allow it to fit over the lever. Carve out a small groove in the tubing with an X-acto® knife.

After fitting the pipe tubing onto the lever, cut two short pieces of dowel rod and insert them into the tubing for stability. When inserting the dowel into both ends of the tubing, establish a snug fit by pushing the dowel into the inside surface area of the lever handle. For added stability, glue the dowel pieces into place after adding the pipe tubing.

A communication board can be developed to allow players to indicate their color choices and start the game. A tape-recorded message of "monkey, monkey, monkey" is another way to indicate the start of the game. Players can also form teams so that the team with the most bananas wins. Go bananas!

Monkey Mania™ is available from Toys R Us™.

Alice Wershing is the Computer Resource Specialist and Toy Program Coordinator at the Disabled Children's Computer Group (DCCG): Technology Resources for People with Disabilities, 2547 Eighth Street #12A, Berkeley, Calif. 94710, (510) 841-DCCG. The author wishes to thank Lisa Wahl for her support during the completion of this article.

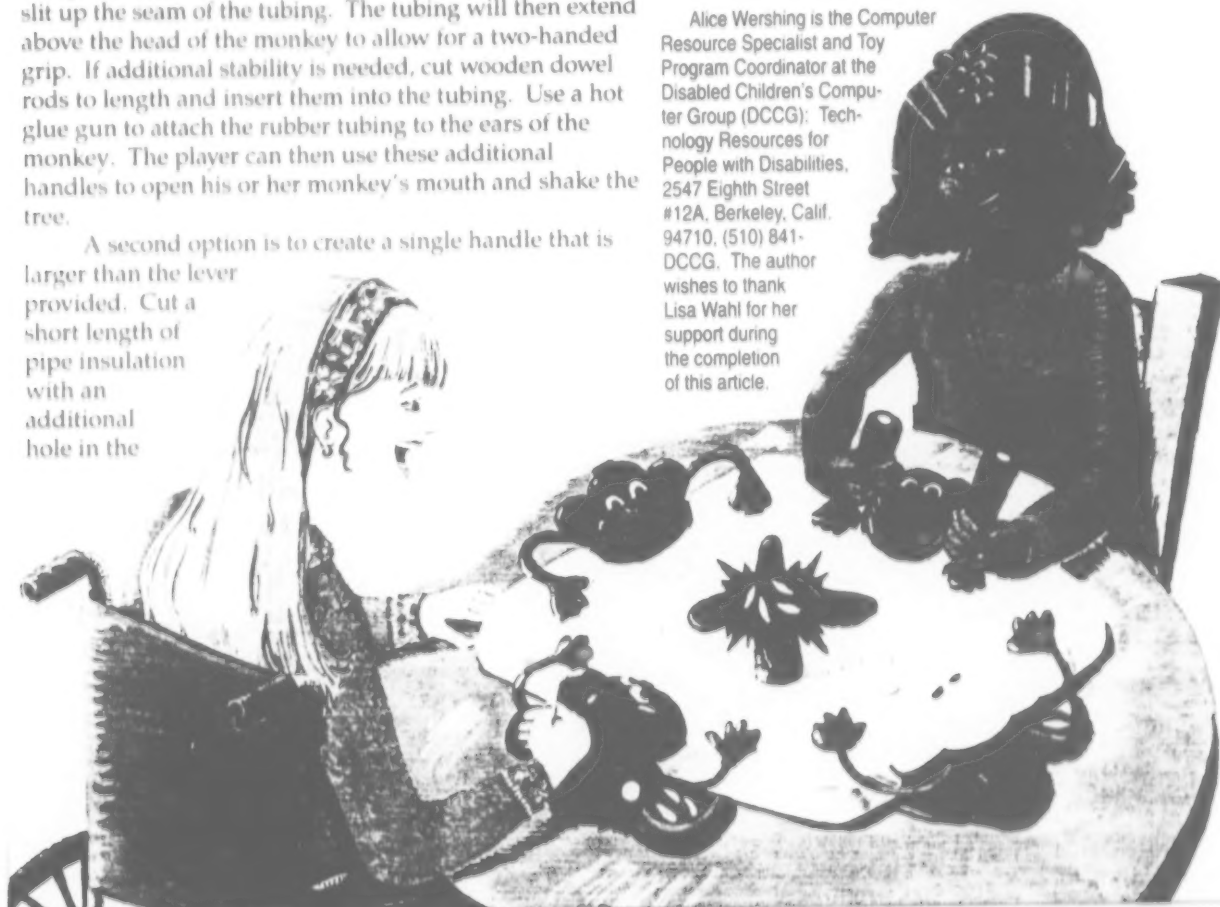


Illustration by Kathleen Johnson Cox



My Best Friend

by Nicole Riegel

I have a best friend. His name is Brett Eller. He lives down the street from me, he has cerebral palsy. Brett says hi, airplane, Papa, Mama and goodboy. He'll also give you kisses. Cerebral palsy children are the same as children who run, jump and walk. A lot of people make fun of him but I don't think it's right. I love Brett a lot. I wish I was Brett's sister. I don't know what else to say about making fun of him. Brett cheers you up. He smiles a lot and gives lots of kisses. He is my best, best friend. He is very cute and he'll say hi to anyone. Brett's favorite food is anything chocolate. He's my best friend and I love him. I am ten and he is seven. He talks to me a whole lot. Brett loves everybody he sees. Even though I haven't been with Brett all his life, he's one heck of a kid.

Nicole Riegel, 10, and her best friend Brett Eller, 7, both live in John, and she has a sister, Ashley. Nicole's a fifth-grader at loves camping, fun field trips and skating. Brett's parents are Center and likes swimming, music and speech therapy with a lot of love and compassion ... (and) her awareness of

Upper Marlboro, Md. Nicole's parents are Elaine and St. John the Evangelist School, is a Girl Scout and Patrice and Mark. He attends the Tanglewood Special Brett's mother says "Nicole is an incredible young girl children with disabilities should be shared with others."

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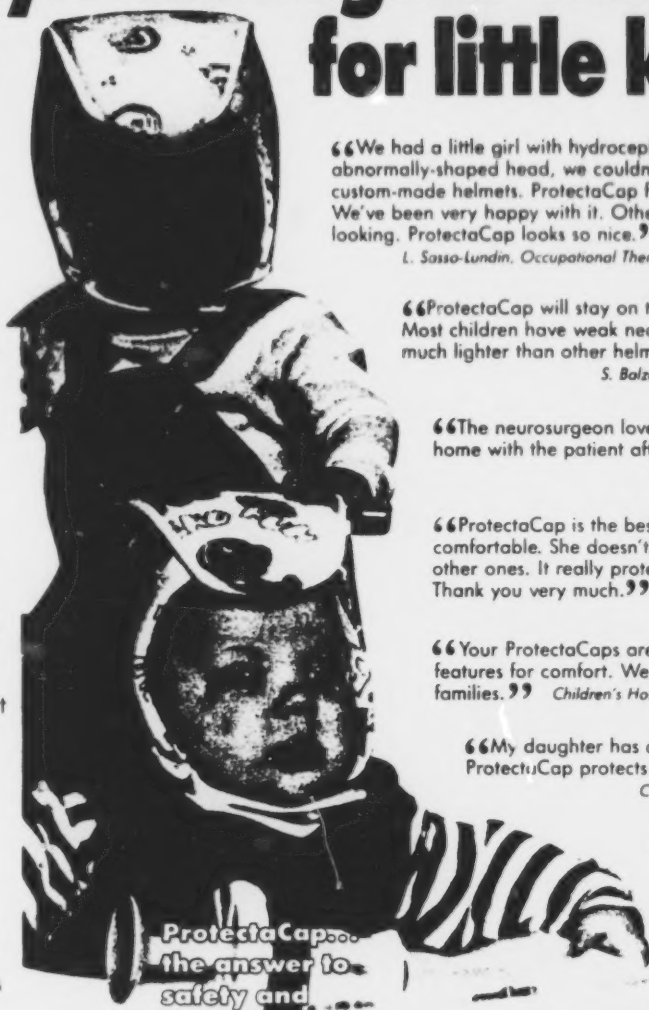
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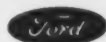
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Cover: Pool Pal, Wisconsin's Nathan Zopf, 5, learns to swim at Cedar Haven Summer Program. See story page 24.

June 1993

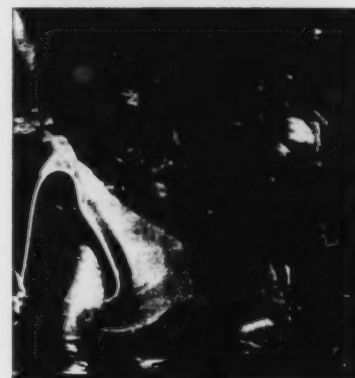
Volume 23, Number 5

FEATURES

- 16 Papa's Sweetheart** *by Catherine Twomey*
One family's special relationship, despite their daughter's disabilities and illness.
- 20 The Merry-Go-Round** *by Wayne Rhodes*
A father's shock and recovery after learning his son has spina bifida.
- 24 1992 Summer Program Awards & Commendations**
Award-winning Hole in the Wall Gang Camp. Also, special commendations.
- 28 Home Beach** *by Deborah Stachunas*
A creative way to take students with disabilities on a fun, hassle-free "field trip."
- 32 Recreation Resource Section** A guide to the special services offered by major theme parks, national parks & national recreation organizations.
- 42 Selecting a Seating System** *by Elaine Trefler*
How to choose the right seating system for your child.
- 51 Networking** Information from the National Parent Network on Disabilities.
- 72 Evaluating Feeding Concerns** *by Ellen H. King*
Where to find help solving your child's feeding problems.



Page 16



Page 24

DEPARTMENTS

- 6 Family Support** Letters to the Editors, Parents Search, Parents Respond
- 14 Editorial** Liberty and Choices for All
- 55 Special Book Excerpt** When Your Child Goes to School After an Injury
- 56 Technology Bulletin Board** ATA Scrapbook of Success.
- 58 From the Bookshelf** Physical Activity for Individuals with Mental Retardation
- 60 What's Happening** Spinal cord injury database, resume service & more!
- 62 Family Life** Conflict about developmental milestones.
- 70 Tips for Parents** Teaching with the VCR; adapting sports rules & more.
- 71 Fun Stuff** *by Alice Wershing* A handful of fun with Slap Happy™.
- 76 Family Album** *by Matt Lutak* Ryan



Page 20

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EDITORS' DESK

This issue we focus on summertime and recreation by presenting the sixth of our Summer Program Award winners, as well as commendations for six additional camp programs. This issue's featured award winner, The Hole in the Wall Gang Camp in Eastford, Conn., was founded by actor Paul Newman and is a residential summer camp for children with cancer and serious blood conditions.



Stanley D. Klein



Maxwell J. Schleifer

Camp Commendations. The following camps were awarded special commendations: Camp Echo Aquatic Camp, East Lempster, N.H.; Camp Fairlee Manor, Chestertown, Md.; Project MAC, New York, N.Y., and featured on our cover, Cedar Haven Summer Program, West Bend, Ind. We also spotlight two camps devoted to helping children with disabilities and their parents learn more about assistive technology: Talking with Technology Camp, Denver, Colo., and IEP+ Camp, Mountaintop, N.J. These wonderful programs illustrate the many possibilities summer camp programs can offer children with disabilities and their families.

Also in this issue, Deborah Stachkunas describes in *Home Beach* how special education teachers can take students with disabilities on a fun, hassle-free field trip without ever leaving the school! We hope this innovative idea will encourage others to treat their students to some beach fun as well.

Our resource section this issue provides recreation information to help liven up your child's (and your family's) summer vacation. We have included a guide to the accessibility of some of this country's major theme parks. Also, we list some wheelchair-accessible national parks, as well as national recreation organizations arranged by sport.

How Families Cope. In *Merry-Go-Round*, Wayne Rhodes offers a father's reflections about his son's spina bifida and how he and his family have dealt with it. Catherine Twomey describes the special support she and her husband have received from their families in raising *Papa's Sweetheart*, their six-year-old daughter with various disabilities and constant illness.

School Mainstreaming Awards

Now is the time to think of nominations for our School Mainstreaming Awards which recognize outstanding programs at the preschool, elementary and high-school levels. To nominate your child's school, send a 1,000-word essay along with a 200-word summary describing the program. Please include photos (both black-and-white and color are welcome). Nominations must reach us by Aug. 6, 1993. Send materials to: EP Mainstreaming Awards, *Exceptional Parent*, 1170 Commonwealth Ave., Boston, MA 02134-4646.

INDEX TO SPECIAL ADVERTISING SECTIONS

SECTION	PAGE #'S	SECTION	PAGE #'S
Van Conversion/Equip. Dealers Guide	33	Marketplace	57
Product Showcase/Advertisers Index	37	Media Buyers' Guide	59
Seating & Positioning Buyers' Guide	49	Schools, Camps & Res. Guide	66

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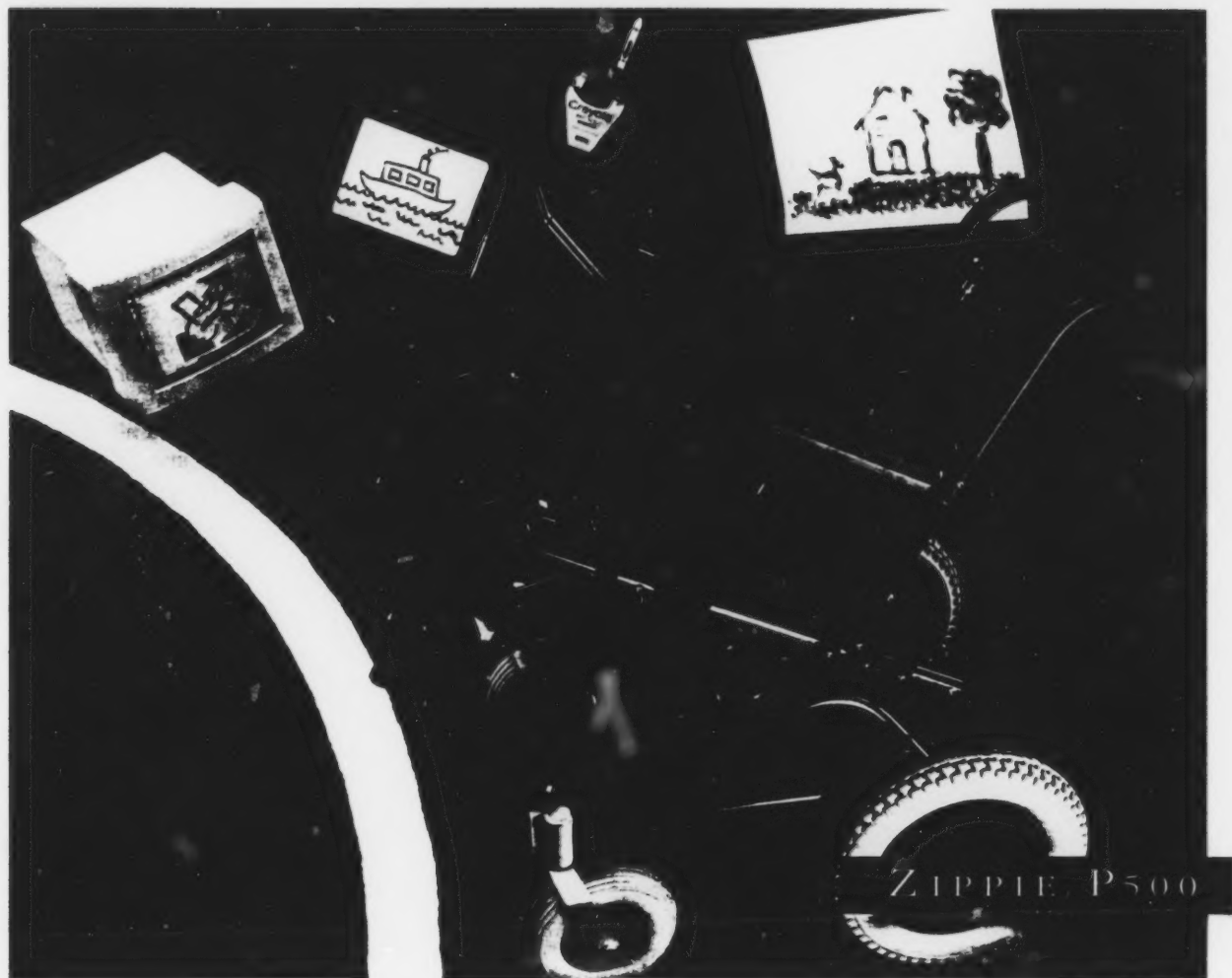
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Letters to the Editors

Profound Truths Author Responds

I wanted to thank you for giving my viewpoint the national attention it deserves in your publication (*Profound Truths*, February 1993). I am impressed with the presentation in your magazine and hope it has generated healthy discussion and criticism within your readership.

In my community, I have received recognition from a special education professor at Keene State College whose students chose to critique the article as an assignment.

As we work out Evan's middle school transition, I am sure I will have more stories to tell. Our experience with Evan has taught us that there are no easy solutions. At the end of this school year, we have some doubts as to the relevance of the inclusion process for our son.

A few weeks ago, I received a long-distance phone call from one of your readers — a mother who was struggling with her decision to place her son with multiple disabilities in a residential facility. The fact that my article gave her the validation and courage to go on was incredibly gratifying to me. Thank you for letting my voice be heard.

Kathleen M. Fagley
New Hampshire

Exceptional Parent Makes the Rounds

I recently started a subscription to *Exceptional Parent* and I've already learned a lot. I am an aide on a school bus for children with disabilities in Lee County, Fla.

The first magazine I received

had a great article in it. I showed it to a parent and never got the magazine back. The next issue came and I lent it out with strict demands to get it back to me. So, in the mornings I let one parent have it and pick it up in the afternoon and let another parent keep it overnight and so forth for the rest of the week. I keep it over the weekend. Its pages are loose; things are underlined, checked and double-checked; pages are marked, bent and torn. I know they can't all order a subscription, so I'll just keep learning and sharing.

B.H.
Florida

Unexpected Brush with the Familiar

My heart seemed to skip a beat when my February 1993 issue of *Exceptional Parent* arrived and I suspected immediately that the precious little blonde on the cover has Rett syndrome. Her hands, gently held down by her sister, must otherwise be in constant motion, her smiling face and expressive eyes convey emotions she can never describe. My daughter Erin is exactly the same. It is disconcerting to see such a rare disorder manifest itself so consistently.

The March issue, in which Kimber and her sister are featured in the *Family Album*, moved me to tears. Like Kimber, my daughter also has a loving older sister. Every aspect of Jennifer's poem describes our daughter.

I benefit from the sense of perspective *Exceptional Parent* offers me, but I was deeply touched by this unexpected brush with the familiar.

M.E.M.
New Jersey

Making Life a Bit Easier

My subscription to your magazine started in March 1988 when my son Kevin was six months old and life was so scary. The magazine helped me cope and adjust to my

son's various disabilities. When Kevin was hospitalized with a shunt infection and returned home in October 1991, I wrote to your magazine in search of others with similar problems. I now correspond with several parents and find the support and compassion overwhelming.

On Oct. 30, 1992, Kevin died at home, peacefully. I am very emotional about Kevin's five years of life and what he brought to our family. His life was one of love and strength.

I still receive your magazine and am constantly reminded of Kevin's life. It is a bittersweet reality. My subscription will end with the June issue, but I will renew it to help me continue to "live" Kevin's life and help other families as *Exceptional Parent* has helped my family. Thank you for making life just a bit easier.

J.F.
Michigan

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- BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, Mich.
- SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, N.Y.
- HERBERT J. GROSSMAN, M.D., C.S. Mott Children's Hospital, Pediatric Neurology, Univ. of Michigan Medical Center, Ann Arbor, Mich.
- GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, New York, N.Y.
- SUSAN M. KLEIN, Ph.D., Professor of Special Education, Department of Education, Indiana University, Bloomington, Ind.
- EDWIN W. MARTIN, Ph.D., President & CEO, National Center for Disability Services, Albertson, N.Y.
- JAMES MAY, M.A., M.Ed., Project Director of the National Father's Network, Bellevue, Wash.
- JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, Ill.
- EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, Pa.
- BETTY PENDER, M.S., Member, New York State Developmental Disabilities Planning Council, New York, N.Y.
- HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, Mass.
- SIEGFRIED M. PUESCHEL, M.D., Ph.D., M.P.H., Dir., Child Dev. Ctr., Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, R.I.
- JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, Texas.
- HARLYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, N.Y.
- BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, R.I.
- HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, Mass.
- CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, Utah.
- HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, Mass.
- IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, Mass.

We welcome all contributions to *Letters to the Editors*. Please send your questions, ideas and responses to:
Letters to the Editors
Exceptional Parent
1170 Commonwealth Ave., 3rd Fl.
Boston, Mass. 02134-4646.

Parents Search

Living with a Terminal Diagnosis

My 11-month-old daughter, Erica, was recently diagnosed with lissencephaly. We have been given so much mind-boggling information about this disability that it is hard to sort out what is helpful.

She is in an infant and toddler program and is doing okay. My problem is that I don't know what to expect from her. Is it true that her life expectancy is three years?

I am very happy to have her. She is a joy to be around, but how do you handle the day-to-day living knowing that this could be your last day with this precious gift?

Her therapy and stimulation classes take up so much of my time while our other two children are in school that if she dies before my time comes, what do I do? I need her just as much as she needs me. How do parents go on from there?

Are there any parents who have advice that can help? How do you go on living day to day with a smile on your face let alone in your heart?

M.L.B.
Maryland

MELAS Syndrome

My two-year-old son, Travis, functions at a six-to-nine-month-old level in his motor skills.

His first six months of life were filled with rigid, constant crying. At five months of age he was diagnosed with bilateral optic nerve atrophy and moderate-to-severe bilateral hearing loss. At six months of age he developed infantile spasms which later changed into myoclonic-tonic seizures. He is on several medications but his seizures are still not controlled.

Travis' overall diagnosis is MELAS (mitochondrial myopathy, encephalopathy, lactic acidosis and stroke-like episodes) syndrome. It is a rare disorder that affects a person in many different ways. It usually

occurs between the ages of three and 10, but Travis had characteristics of the syndrome before birth.

We were told that Travis may live six months, five years or even 50 years. His prognosis is unknown because no one diagnosed with MELAS has been so affected by the syndrome at such an early age.

I would like to correspond with

any parent who has a child with MELAS syndrome, uncontrolled seizures or who is deaf or blind. I would like to share information and swap ideas.

T.D.
Texas

Seeking Durable Clothing

We have two children, both with different problems. Our son has multiple disabilities, including autism,

continued on page 8

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continued from page 7

vision loss and a hearing impairment. He is also mute. Our daughter was born with a bilateral cleft palate which required multiple surgeries.

Currently, our main concern is finding clothes for our son that he cannot tear. He shreds his clothes when he is frustrated, even denim jeans which are not easily torn.

If someone knows of a clothing manufacturer which produces more durable clothing, please contact me.

N.D.P.
Oklahoma

Teeth Grinding and Biting

My 20-month-old son, Cameron, has a mitochondrial disorder. His main problems are grinding his teeth, biting his tongue and chewing the sides of his mouth. His mouth bleeds and gets very sore when he does this. He seems to do it when he has air in his stomach or when he gets new teeth.

We had our dentist make a mouth guard to keep him from biting, but every time a couple of teeth push through, it is ineffective and we have to have another one made.

I would like to know if other parents have this problem and if they have any suggestions.

M.M.
Pennsylvania

Life After High School with Mental Retardation and Psychiatric Disorders

My 16-year-old adopted daughter, Crystal, has mental retardation and has also been diagnosed with psychiatric disorders such as bipolar illness, psychosis, schizophrenia and autistic-like behavior (she has some symptoms of each of these disorders).

She is fairly stabilized on medication and attends special education classes at the public high school, but she needs to be monitored at all times because of her inappropriate behavior and her tendency to wander

F.Y.I.

An Overview of Beckwith-Wiedemann Syndrome (BWS)

Beckwith-Wiedemann syndrome (BWS) is a congenital growth-related disorder. This syndrome usually occurs randomly but may be inherited. These children are at risk for developing hypoglycemia and various types of tumors. The incidence of BWS has been reported as approximately one in every 15,000 births, but exact figures are not available because there are many mild cases that are not diagnosed.

The syndrome is thought to be caused by an alteration in the genes of the child. Some cases are thought to be new mutations when no other relative has the disorder, while other cases appear to be inherited from a parent.

There are roughly 30 characteristics that can be associated with BWS. It is very rare for a child with BWS to have all of the characteristics; most cases only have a few of them. Some of the most common include an enlarged tongue, abdominal wall defects, increased growth and an enlarged back of the skull. Some of the distinctive features of BWS may need to be corrected, but most of them diminish and disappear with time.

When certain characteristics are present, prenatal ultrasound can sometimes be helpful in the diagnosis of BWS. An omphalocele is the easiest to detect. Other characteristics that may indicate BWS include enlarged abdominal circumference, enlarged kidneys, enlarged placenta, increased amniotic fluid or protruding tongue. Currently, there is no definitive blood test for BWS, although an elevated Alpha-fetoprotein level in the presence of an omphalocele may help in the diagnosis.

Hypoglycemia (low blood sugar) affects a small percentage of reported cases of BWS. Hypoglycemia rarely lasts more than a few weeks and usually responds to either IV glucose, medication and/or diet, depending on its severity.

The incidence of malignant tumors in reported cases is about 5 to 10 percent. The most common malignancy is the Wilm's tumor of the kidney. Due to the aggressiveness of some of the tumors associated with BWS, screening by ultrasound every three months until about seven years of age is recommended.

Resource: *What is BWS?* was produced by the Beckwith-Wiedemann Support Network (BWSN).

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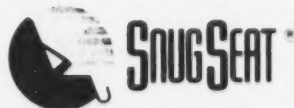


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away. I am wondering what kind of life Crystal will have once she is out of high school. What would be the best setting for her? I am interested in hearing from any parents who have had similar experiences.

In addition, do I have the right as her parent and sole guardian to decide that she should never have children of her own? I feel she would be unable to care for a child properly. Also, all of her conditions are inherited, so they would be passed on to her children.

W.J.B.
Illinois

Negligent Hospital Testing of Primary Hypothyroidism

I have a six-year-old daughter who was born with primary hypothyroidism. When this is diagnosed at birth through state-required blood tests for newborns, it is usually not a problem. The baby is immediately started on a thyroid replacement

medicine and is eventually all right.

My daughter was not so lucky. The hospital forgot to do her newborn screening tests before we went home. After three months of problems, including constipation, poor sucking, lethargy and two hospital stays, it was discovered that there were no results in her records to indicate the tests were ever done.

After the test was finally administered, we found out that she does have hypothyroidism. She is delayed in all areas but is very intelligent. Her main problems are with her speech and attention span. The best diagnosis we've been given is pervasive development disorder.

She has been going to a terrific developmental preschool for three years and has made some great progress, but like any parent of a special needs child, I'm looking for answers and information anywhere I can.

I would be very interested to know if this has happened to anyone

else. I would also be grateful for any kind of information on doctors, therapists or studies on this subject.

K.H.
Missouri

Progress with Microcephaly and Mental Retardation

My seven-year-old son, Aaron, was a full-term baby, delivered by C-section because of inadequate delivery space. He scored a 9-10 on his Apgar test. When he was taken in for his two-week checkup, we were told that he had lost too much weight due to failure to thrive.

Another checkup at three months of age showed a marked drop in the circumference of his head with normal growth in length and weight. Close monitoring from three to six months of age showed a drop in head circumference from 25 percent to 5 percent. We were referred to a pediatric neurologist but nothing unusual was found after a CT scan.

continued on page 10

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Tilt-In-Space

continued from page 9

When he was two years old, we were told he had microcephaly with mild-to-moderate mental retardation. We were also told that he would never talk, might never walk and possibly would not toilet train until much later in life. The clinic had only two other cases on file and neither had made any progress.

Aaron did not sit unassisted until he was eight months old, crawled at about 12 months and only made

grunting sounds. He learned to walk with the aid of a walker equipped with wheels. After six months of this, he walked alone.

He entered an early intervention program and learned to talk very well. Now at age seven, he uses full sentences and communicates better than we ever expected. With behavior modification techniques, we were able to toilet train him at age six.

We would like to correspond with other parents of children with

similar diagnoses. Aaron has far exceeded everyone's expectations. Perhaps we can encourage other families and offer information that will help them cope.

T.N. & L.N.
Mississippi

Emotions Involved with Residential Placement

I am the parent of a 10-year-old boy who is autistic and mentally retarded. He is now in residential placement.

My son has been living in a residence home for two years now. Even though we see him every weekend and are extremely involved in all of his care, we are still dealing with the pain and loss of not having him home with us.

If there are any parents in similar circumstances, I would like to hear from you.

V.S.
New York

Townes Syndrome

We adopted a two-and-a-half-month-old boy three years ago. He has been diagnosed with Townes syndrome with birth defects. He was born with a hole in his heart and is visually impaired. He weighs 16 pounds but is 34 inches tall. He is a beautiful child. He eats well and is the joy of our lives.

If there are other parents who have children with Townes syndrome, we would like to hear from you.

P.S.
Washington

Seeking Activity Ideas to Help Kids Accept Students with Disabilities

I am 12 years old and in the sixth grade. I have a brother with attention deficit disorder.

I have seen a lot of discrimination at my middle school. Next year I am starting a club called Stop DADK (Stop Discrimination Against Disabled Kids). My idea is to get a team together to make the school a better place, to teach nonviolence and help

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Does anyone have any ideas of activities this club could do and how you can help people accept kids with disabilities?

A.H.
Colorado

Editors' Note: Jill Krementz's book, *How It Feels to Live with a Physical Disability*, can provide insight into the lives of children with disabilities. This collection from 12 children with disabilities, ages six to 16, allows these children to tell their own stories. It is available through *Exceptional Parent*, 1170 Commonwealth Ave., Boston, Mass. 02134.

ADHD and Mental Retardation

Our three-and-a-half-year-old daughter, Kayla, has epilepsy, ADHD (attention deficit hyperactivity disorder), a heart murmur, ataxia, mild-to-moderate mental retardation, mouth and teeth malformation and a sleep disorder.

Everything is overwhelming, but we are having the most trouble with the ADHD/mental retardation. I have not been able to find anything on kids with both of these problems or effective ways to deal with them.

I would like to correspond with parents of children with both of these disorders.

J.R.
Minnesota

Big Diapers!

Diapering a child with multiple disabilities becomes a challenge after the child outgrows toddler-size diapers. I am rapidly approaching that challenge.

My daughter has the ability to stand if supported and is working toward toilet training even though, realistically, it may take years for her to accomplish this, if she ever does.

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continued on page 69



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Parents Respond

Gum Swelling

Response to B.B.'s Parents Search,
February 1993.

We have an 11-year-old daughter, Ana, who has had multiple disabilities since birth (cerebral palsy, mental retardation and a seizure disorder). From the beginning, she has been on anticonvulsant drugs, including Dilantin. As time passed,

her gums became extremely swollen and her teeth were unable to fully cut through.

We visited several oral specialists and all of them agreed that surgery was the only possible way to reduce her gums. There were different opinions regarding which kind of anesthesia to use and when the surgery should be performed. The

first step toward surgery was to switch our daughter's medication from Dilantin to an equivalent drug.

During the next few years, Ana's seizure disorder diminished significantly. Under the care of a pediatric neurologist and an oral specialist whose main practice is with children with disabilities, we were able to begin her withdrawal from Dilantin and introduce the substitute drug, Tegretol. Several months later, the swelling of her gums was greatly reduced but surgery was still necessary.

In December 1992, Ana underwent oral surgery as an outpatient and recovered admirably well. She looks beautiful and is very happy about it.

Her intake of fluids has increased and she's eating faster and better so we are beginning to introduce different textures.

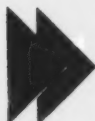
My advice to you is to continue gathering information and consulting specialists until you find the most appropriate one. No one can give you the perfect solution. Remember each child is different.

A.M.L.
Florida



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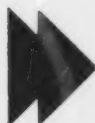
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Brachial Plexus Injury

Response to M.B.'s Parents Search,
March 1993.

I sustained a brachial plexus injury 75 years ago which also included a fractured humerus (undiagnosed until age eight). I have difficulty raising my right arm and turning my hand over.

What I'm really trying to tell you is that as distressing as it is to have this happen to your little girl, with your encouragement and all the therapy that is available these days, the chances are good that she will live a full life. She will learn, as I did, to compensate for the very few things she may not be able to do.

I know that my mother had much more difficulty accepting my disability than I ever had and I grieve for her pain.

M.G.
Massachusetts

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Liberty and Choices for All

In the February 1993 issue of *Exceptional Parent*, we published *Profound Truths* by Kathleen M. Fagley in which she described her family's decision in 1984 to place their three-year-old son, Evan, in a residential program. We received an almost instant response from you, our readers. Some parents were thankful that the use of residential placement was discussed. Others expressed their disappointment and anger at families like the Fagleys and have continued to criticize *Exceptional Parent* for publishing articles about residential placement. We are concerned because the letters we have published suggest that loving, caring parents are fighting with one another, somehow becoming polarized on this issue.

Attitudes about residential placement have a long history. Some critics seem to continue to equate placement in a contemporary residential program with the inhumane and tragic institutionalization of children and adults with disabilities that was so common 20 to 30 years ago. Although we must not forget our vivid, personal memories and the horrible photographs of the way our society treated children and adults with disabilities in the past, there have been vast changes, unimaginable three decades ago.

When we first began *Exceptional Parent* in 1971, there were so few alternatives for the care and education of children with disabilities that institutionalization was often the only option families could afford; the family's only decision was whether to place the child today or sometime in the future. In the minds and hearts of parents, institutionalization was viewed as a sentence to life in prison, or even a death sentence.

While in the United States today there still exist some troubling institutional settings that isolate residents separated from communities and/or fail to provide humane care, parents and people with disabilities have choices — choices that are no longer the "lesser of two evils." Many residential programs offer a variety of creative programs that include many opportunities for community participation. And yet, although there are decent choices available today, why do so many caring and dedicated parents and professionals continue to react angrily to articles and advertisements about residential programs for children and adults with disabilities?

First, although much has changed, parenting has always been, and will continue to be, a challenging, energy-consuming, stressful and usually thankless task. Parenting a child with a disability and/or special health care needs will continue to be even more challenging, energy-consuming, stressful and thankless. Thus, it

becomes especially important for each of us to remember that under stress, good people can think and say things which they wish they had never said. For example, under the stresses and anguish of everyday life, all people, including parents, may occasionally feel like getting rid of individuals they love. Unfortunately, some parents keep these troubling feelings and thoughts to themselves because they are angry and upset with themselves for having such feelings and fear sharing them. Under the stress of the moment, when these feelings are put into harsh words or deeds, parents may abuse the child or spouse they love — thus, when we are upset we are likely to say to do things that we regret. As stresses continue and personal energy becomes depleted, individuals and families can become exhausted as well as unable to cope in ways that are supportive of a caring, loving household.

Second, all parents share parenting's greatest challenge — to assure that each child receives the best possible education and health care. Despite the vast changes that have taken place, parents of children with (and without) disabilities are forced to settle for less than the best in both education and health care. Under such realities, many parents decide to enroll their children in private or religious day schools or boarding schools — sometimes choosing to greatly increase the family's financial stresses. Others, without adequate resources, are forced to make compromises or to fight for public funding from limited public resources. Then, whenever a placement decision is made, public programs for other children may suffer.

We respect all parents and we believe that parents always know best about the needs of their own children. We also believe that each family tries its best to make the most constructive decisions for each of its members.

We believe that all parents are entitled to opportunities to make the best possible choices for all their children. At the same time, we continue to be enthusiastic supporters of the inclusion of children with disabilities in public education classrooms with their neighborhood peers — as long as such programs continue to attend to the special needs of children with disabilities and the needs of the other children, teachers and parents. We will continue to advocate for the right of every parent to choose the best for every child. And we shall not abandon our hope that someday, each parent shall have many wonderful choices for each child as well as for themselves.

— S.D.K. & M.J.S. —

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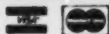
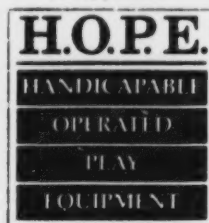
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Papa's Sweetheart



BY CATHERINE TWOMEY

I just picked up some new pictures of my beautiful six-year-old daughter, Allison. While I was looking at the pictures, I was suddenly struck with the desire to brag about my little girl.

I cannot begin to describe the agony my daughter has endured since her birth six years ago, nor can I adequately describe the joy she has brought to my husband and me. Her stubborn determination and her great love for us and for everyone in her life are inspiring.

She was born after a normal pregnancy and immediately had trouble breathing. She spent the next five weeks in a neonatal intensive care unit. During that time, we discovered that Allison had very low muscle tone and facial paralysis. She had to be tube-fed and could not blink. In fact, her eyelids were so droopy they were almost closed, but her vision was and still is pretty good. She was seven months old, however, before we were certain she had to have tracheostomy surgery to help her breathe.

On July 1, 1986, we finally took Allison home. She had a tracheostomy tube, a feeding tube and an apnea monitor, but no diagnosis. We had no idea what to expect. After seeing many other doctors, we took her to the Mayo Clinic where a neurologist finally diagnosed that she had congenital hypomyelinating encephalopathy, meaning she has very little myelin insulating her nerves.

It was not until a couple of years later, during a follow-up visit, that we realized the extent to which this doctor was amazed by our daughter. Based on what he

knew about the importance of myelin, he had expected Allison to be completely nonfunctioning, both physically and mentally. As it turns out, we (and her doctors) believe that her cognitive abilities are normal, despite a lot of physical obstacles. Her muscles are weak but getting stronger all the time. She crawls all over the place and can walk some with a walker. She can now sit very well and has good fine motor skills.

Every doctor we have taken her to has been amazed that when Allison was only four months old, she began holding her eyelids open one at a time with her thumb to help her see. She did this with great speed and accuracy — she never once poked herself in the eye. Just for variety, she would sometimes even use a rattle to hold her eyelid. Allison could not crawl because she needed one hand to help her see. When she was three years old, she was finally able to have surgery to lift her eyelids. She began to crawl the very next day!

When Allison was two years old, she had her tracheostomy tube removed. She has had no breathing problems since.

Allison's Illnesses

By far the worst of Allison's problems is her illness. It started when she was a year old. She would stay "well" for about seven days and then she would be very sick for the next seven days. At times she vomited so much we had to feed her nothing but Pedialyte for days just to keep her hydrated. This has been going on for five years. The pattern is erratic at times and she vomits less now, but essentially she is sick 50 percent of the time. It is a nightmare for all of us. So far, her doctors cannot find any way to help her, but they are still trying.

At age six, Allison is making wonderful progress! Speech has always been very difficult for her because of the facial paralysis. Even though her hearing is normal, my husband Patrick and I began teaching her sign language when she was about two years old. Patrick and I had to teach ourselves first, so unfortunately, Allison often had to wait for us to learn the signs she needed.

By the time she was five, she had a sign language vocabulary of over 300 words and could sign the alphabet and numbers one through 10. Her verbal skills amounted to about 20 words. Now, a year later, she has pretty much stopped adding to her sign vocabulary but her verbal skills consist of over 200 words. It is now difficult to keep track because she says new words almost every day. She often uses five- and six-word sentences. She will attempt to say almost any word we ask her to, even though she has to use her hand to push her lips together to make bilabial sounds like "b," "p" and "m."

She is still tube-fed, but loves to taste food and can now eat small amounts of baby food. Her feeding skills are improving slowly and steadily.

Often I am overwhelmed by my daughter's ability to live her life with such strength and determination, only seven days at a time, despite so much illness. When she is sick, she is very sick. It makes her very angry and sad, yet she never shows the slightest sign of bitterness once the illness is over. She refuses to waste any of her "well" time. I used to be afraid that Allison would look at me while she was sick and wonder why I did not do anything to help her. I am so thankful that she understands how much I love her and that I would do anything to help her if I could. She actually seems to make a special effort to tell me she loves me when she is the sickest. Many times she has even gained new skills in the middle of an illness. Several years ago, she pulled herself up to a standing position for the first time while she was sick.

Good Days

When Allison is well, life is wonderful! She is so sweet and funny and very loving. She is always telling Patrick and me that she loves us and she is always kissing us. Allison is very lucky to have the best grandparents, aunts and uncles she could hope for. They all live far away from us, but we see them as much as we can. Allison loves them all and talks about them a lot. She especially loves to talk to her Grandma and Grandpa (who she calls Papa) on the telephone. Ever since she was a baby, my Dad has told her that she's "Papa's sweetheart." When she was about two years old, I

finally taught her to sign "Papa's sweetheart" as a surprise for my dad. The next time she saw him, she immediately signed "Papa's sweetheart" for him. My dad loved it! Now every time she sees her Papa, the first thing she does is say "Papa" (she can speak the word now) and sign "sweetheart." I have a feeling this ritual will continue for a long time to come.

Allison's main goal in life right now is to have fun.

We go for walks to a nearby park

where she swings and goes down the slide. She says she wants to swing up to the sky. She loves to paint at her easel and write on her chalkboard. She has just begun to teach herself to write the letters of the alphabet. So far she can write "i," "l," "t," "m," "x," "o" and "h."

She has been learning all this by herself — she keeps calling me over to her chalkboard to show me what she has written!

Allison loves to listen to music and dance. She especially loves to dance with her Daddy and her Papa. Allison has unusual musical taste for her age. She likes Mozart, Fats

Domino, Nat "King" Cole, Van Morrison and her very favorite — Ella Fitzgerald. She is very particular about who she wants to listen to at any given time, and, believe me, she knows it if I try to sneak something different past her. She has her own autographed picture of Ella Fitzgerald. We have to take the picture down off the wall almost every day so she can look at it.

Even before Allison could talk, she had a real sense of humor. One summer, when she was two years old, my husband (who is an Episcopal priest) spent a week as chaplain at a church camp for nine-year-old kids. A friend of ours took Allison and me to the camp to visit one day and we arrived in the middle of an outdoor worship service. They were singing a camp-type Christian song and my friend and I were innocently joking about the song because it was just not our style. Every time they came to the end of the refrain, "Have you seen Jesus in my Lord?" Allison would very emphatically shake her head "No!" Every time! As I said, she has very definite musical preferences. She has never really liked cute, sing-songy children's music. One time I turned on a new children's tape that someone had given her and she

*I am overwhelmed by my
daughter's ability to live
her life with such strength
and determination.*



Allison and her "Papa" ride Clyde, her special horse handmade by Papa and Allison's three uncles.

continued on page 18



Allison using her walker.

immediately began to cry and sign "turn the tape off!"

She does love some children's songs, but only when someone sings them to her. Her favorites are *The Eensy Weensy Spider* and *Twinkle Twinkle Little Star*. She loves songs with hand motions that she can do herself. She also likes me to sing a few words of a song and then stop; she will say the word that comes next.

Allison has become a well-behaved and helpful

little girl. If she hears one of us washing dishes, she will crawl to the kitchen as fast as she can and beg us to let her help. She is very good at rinsing. I also do not dare vacuum or fold laundry without letting her help.

The Future

I plan to take full advantage of her desire to help when our new baby arrives. We are currently waiting to adopt a newborn baby. We do not know how much longer we will have to wait, but Allison is very excited

about the prospect of being a big sister. She tells me that she will give the baby a bath and rock the baby. I hope this participation will help her to still feel important even though she will not be the only child anymore.

Patrick and I are trying hard to prepare Allison, as much as possible, for life in this sometimes very cruel world. Unfortunately, the older she gets, the less tolerant some people will be of her disabilities. I am afraid Allison's intelligence will make her painfully aware of the insensitivity and cruelty of other people. Thank God this world is also filled with a lot of wonderful, compassionate people who will admire Allison for all the obstacles she has overcome and accept the things that still make her different.

Patrick and I love Allison so much and we are eternally grateful that she is our daughter! EP



Catherine Twomey, a homemaker, lives in Dixon, Ill., with her husband, Patrick, and daughter, Allison, 6. Twomey has a bachelor's in elementary education from Oakland University in Rochester, Mich. She is very active in St. Luke's Episcopal Church where Patrick is a priest. The Twomey family is still waiting to welcome an adopted newborn baby into their home.

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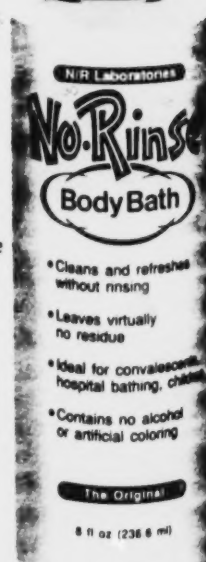
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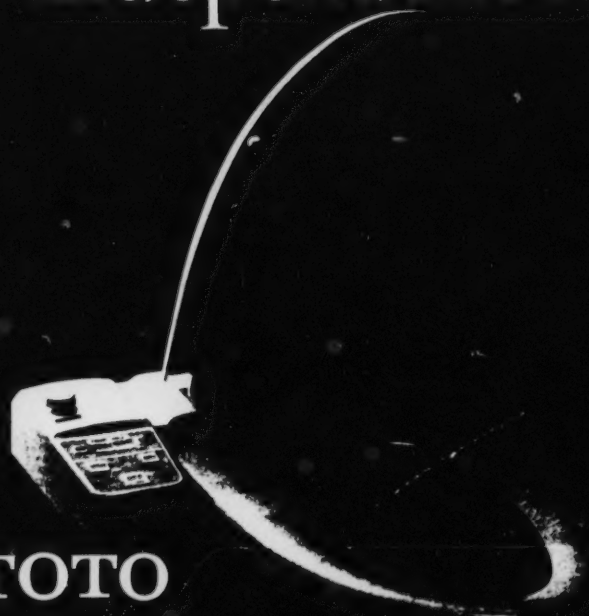
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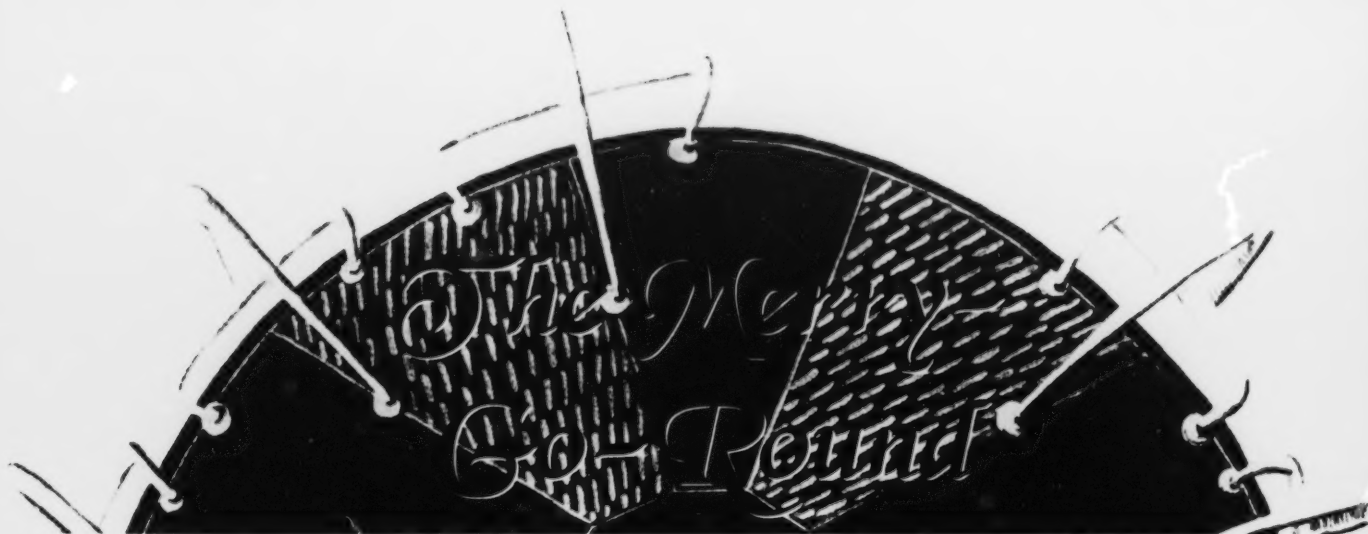


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309



by Wayne Rhodes

This is the story of how I was affected by the birth of my son Jacob. He was born Aug. 14, 1984, with spina bifida. My wife and I had previously lost our first two children and were devastated by the possibility of another loss. Should our son survive we faced an uncertain future.

This is how we managed this difficult time in our lives.



On the day of my son Jacob's birth, I looked upon his tiny body with fear and apprehension. A day that should have been filled with joy had suddenly become dark and foreboding. So many questions unanswered, too many uncertainties. Would he survive the complications of his disabilities? How would our family be affected? We had already suffered the loss of our first two children — could we bear the loss of another? Would we be able to cope with the stress of rearing a child with disabilities?

I was reminded of my first merry-go-round — it was the schoolyard favorite. I recall the good, smooth feeling of the metal, polished by the use of many small hands. The worn wooden seat with faded orange paint. The circular path where everyone ran and pushed before jumping aboard. The squeals and shrieks of merriment as we went faster and faster.

I also remember the day it all changed, when I was swept from my feet as I attempted to push harder and faster. I recall the despair as I struggled to gain a place on the once friendly seat. No matter how hard I tried, I could

not climb back on. From that day forward, the merry-go-round would no longer stand for just fun and joy. Its once benign image was changed forever; it now embodied fear and caution.

After Jacob's birth, life had begun to spin faster than my legs could run. My feet were leaving the ground; my only hope was to hold on with all my strength. Would I make it? Would my family survive? Could I survive? Or would I lose my grip and be flung out into space to await the inevitable crash with the hard, rocky ground? Perhaps I would be flung so hard, so high and so viciously that I could only wonder when, if ever, I would hit the ground.

Between the moment the doctor told me that Jacob had spina bifida and the moment the nurse asked me if I needed to sit down, I felt as though I had travelled at the speed of light to a place I had never been. I knew upon my return that my world would never be the same.

Jacob was immediately transferred to Le Bonheur Children's Hospital in Memphis, Tenn., 140 miles from home. There he would undergo the first of six surgeries before the age of two.



*As you ride the merry-go-round of life and the ride gets bumpy
and you are thrown off, pick yourself up and get back on
"cuz it's more funner than it hurts."*

It occurs to me as I write this what it must have been like for my wife, Anita. Articulate and attractive, she is a people-oriented person who was very popular among her students at the University of North Alabama where she was a psychiatric nursing instructor. After experiencing the grievous loss of our first two babies, Anita formed a support group for families that had experienced the death of an infant. She knew as a mother and a professional that society often discounts the loss of an infant, especially if that loss occurs before or near birth. It was her concern and sensitivity that nurtured and contributed to the healing process of so many.

It didn't seem fair that we might be faced with the loss of another child, yet here she was beside me less than 24 hours after giving birth, making a grim trip to a strange city, facing the unknown. After the normal birth of our daughter Sarah, I once joked with her that Indian women would often give birth on the side of the trail and catch up with the tribe before nightfall. Little did I know that she would accomplish a comparable feat. She never complained and would not stay behind. She insisted on being with her baby. I believe that as we made that journey to Memphis we were both fixated on what lay before us.

Hope and Survival

Somehow we all survived those difficult days, although we often wonder how. It was difficult to watch Jacob struggle against the odds. The doctors were cautious and guarded with their prognosis. They counseled a "wait-and-see" approach. They really couldn't answer our questions or calm our fears. Even though we knew that, we asked anyway.

Following Jacob's shunt operation (to prevent fluid build-up on the brain that causes an enlarged head), he developed bilateral vocal cord paralysis that began to close off his windpipe. His breathing became labored and raspy. We were advised that he would have to be trached, a procedure where a tube is placed in the trachea to facilitate breathing.

We were back on the road to Memphis again. I will never forget that trip for the rest of my life. We felt utterly helpless as we drove with anxious faces and raw nerves — it seemed as though Jacob's breathing had become even more labored, if that was possible. It just didn't seem fair for him and us to have to suffer so much.

As we awaited Jacob's recovery from surgery, we tried to talk our way through our fears. We both knew that Jacob should be developing a smile and signs of

continued on page 22



Sarah and Jacob roughhouse with Dad (above left); Jacob and other campers meet Bambi at Camp ASCCA.



Jacob takes center stage with his relatives and friends.

recognition if he was developing on a normal curve. So far, we had not seen those signs. We knew he had been under terrific strain since birth and hoped he was developmentally delayed for this reason — he was, after all, only eight weeks old. We feared the worst and hoped for the best.

It was with a great deal of apprehension that we approached Jacob's cradle in the infant critical care unit. He wasn't crying. I realized then how accustomed we had become to his loud, raspy breathing. Concerned, we quickly stepped over to his cradle to make sure he was okay. When he turned his head and saw us, a big smile lit up his face. It was like looking out a window on a cloudy, dismal day when suddenly a ray of light bursts through and brightens the day.

As I think back to that day, I am overcome with the emotion that his smile produced in me. It was as close to magic as I will ever be. I knew at that instant that it really didn't matter that Jacob would be somewhat different or have disabilities. What mattered was that he would need to be loved and nurtured to the best of my ability. The fears remained but they had been greatly diminished by the radiance of the smile on a little child's face.

Facing the Future

We have weathered the storm of our earlier fears and are braced to face those of the future. Jacob is six years old now and quite the rough-and-tumble little boy. Like other six-year-olds and his father before him, he too

loves the playground. One of his favorites is the merry-go-round. He found, like his father, that if you lose your balance, the ride on the merry-go-round will no longer be as it was before. I was there when he took his fall. I rushed to his side as he fell in a dusty heap. He was frightened, bruised, scratched and crying, but otherwise unhurt. He announced with tears coursing down his dirty cheeks that he would never ride that mean old thing again. As we examined his bruises and scratches and he was becoming increasingly proud of the one that was bleeding, he looked up when he heard the other children squealing and laughing as they rode round and round. With the tears on his dirty cheeks not yet dry, he announced that he would ride again because, "I'm not scared now, Dad, cuz it's more funner than it hurts."

Life is like that, you know. We learn it from the very beginning, but somewhere along the way to adulthood, we develop fears of another kind. We fear not only for ourselves but for our children and their future. We fear for what they will experience or what we are afraid they won't experience. We fear for the quality of their lives and that society will not accept them as they are. Eventually, we may become immobilized by the fear of fear itself.

We must accept the challenges of life and conquer our fears lest we fall by the wayside and watch the merry-go-round of life pass us by. For our own sake and the sake of our children, we must conquer our fears so that we will be able to nurture and encourage them to develop to the greatest of their abilities. So remember as you ride the merry-go-round of life and the ride gets bumpy — if you are thrown off, pick yourself up and get back on "cuz it's more funner than it hurts." *EP*

Wayne Rhodes lives in Jackson's Gap, Ala., with his wife, Anita, and children, Josh, 16, Sarah, 10, and Jacob, 8, who has spina bifida. Wayne is the assistant administrator at Camp ASCCA (Alabama's Special Camp for Children and Adults), a year-round camp for people with disabilities in Jackson's Gap, where his wife is medical director. Rhodes has a master's in guidance and counseling and a bachelor's in sociology, both from the University of North Alabama.



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1992 Summer Program Awards

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Contact: James Schaffer, The Hole in the Wall Gang Fund, 555 Long Wharf Drive, New Haven, CT 06511, (203) 772-0522.



Photos by Robert Benson.

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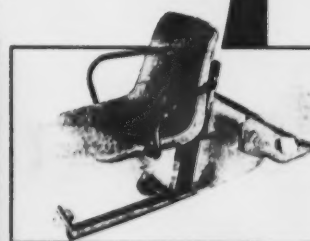
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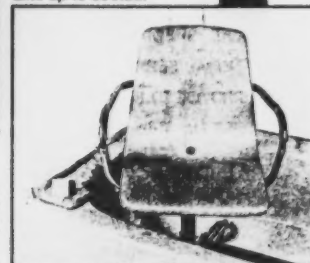
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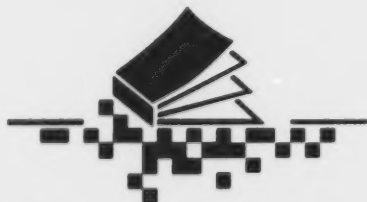
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IEP+ Camp Mountainside, New Jersey

Children's Specialized Hospital in Mountainside, N.J., hosts a summer camp program called IEP+ Camp for nonspeaking children who use augmentative and alternative communication systems. All children attending the camp use a Minspeak™ communication system with the Interaction, Education and Play® software.

Two week-long camp sessions, the first for ages 5 to 7 and the second for ages 9 to 13 are held. Two community agencies play a primary role in the operation of the camp program. The Westlake School provided classroom space and Trailside Nature and Sciences Center offered daily programs and a true camp atmosphere. By the end of each camp session, children and parents alike have enhanced their skills in communicating with IEP+. Parents also develop a strong support network. Plans are underway to create an advanced level camp so these children and their parents can return to the program.

Contact: Dr. Joan Bruno, Program Dir., Children's Specialized Hospital, 150 New Providence Rd., Mountainside, NJ 07092, (908) 233-3720, ext. 339.

Project MAC Frost Valley, New York

Project MAC (Mainstreaming at Camp), sponsored by the Young Adult Institute in cooperation with the Frost Valley YMCA, serves children and young adults with developmental delays. Project MAC is dedicated to integrating and mainstreaming all campers according to individual ability and providing an educational and fun summer experience.

Campers attend from two to five weeks and participate in a variety of sports, arts and

crafts, horseback riding, swimming, hiking, archery and physical education, all supervised by trained staff members.

Activities are designed to promote friendships and build self-confidence, teach decision-making skills, responsibility and cooperation and foster independence.

Project MAC also has a Wellness Program which promotes physical and mental well-being through nutritional meals, a fitness and exercise program and self-care training.

Contact: Iran Buckler, Young Adult Institute, 320 West 13th Street, New York, NY 10014, (212) 645-1616.



Camp Fairlee Manor Chestertown, Maryland

Camp Fairlee Manor runs five week-long sessions during July and August and offers activities adapted to the age and ability of campers with disabilities to help them achieve independence.

The camp features a wheelchair-accessible swimming pool and garden, hiking trails, a bass-stocked farm pond, a petting zoo, nature study, canoeing, camp-outs, arts and crafts and sports and recreation. All buildings, bathrooms and walkways are accessible, and side-walks are textured for those with visual impairments.

Campers are aided by 15 trained counselors and two nurses. The camp now serves as many as 300 campers of all ages and disabilities during the summer season.

Contact: Rozie Zappo Cassidy, Easter Seal Society of Del-Mar, Inc., 61 Corporate Circle, New Castle Corporate Commons, New Castle, DE 19720-2405, (410) 778-0566, (302) 324-4444, (302) 324-4442 (TDD).

ASSISTIVE TECHNOLOGY COMMENDATION

Talking with Technology Camp

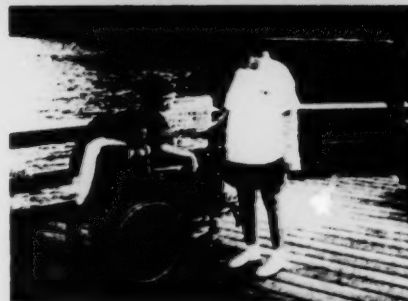
Denver, Colorado

Talking With Technology Camp (TWT), affiliated with the Children's Hospital of Denver and the Colorado Easter Seal's Handicamp Program, is a one-week camp for young people ages 6 to 21 who use augmentative communication systems. Campers learn to do more with their systems while professionals see how communication impacts their patients' lives and environment.

Each camper who uses the augmentative communication system usually attends with a professional who knows the child. Siblings may also attend the program. Parents do not attend, although they do have contact with the professionals and other staff.

Campers receive individualized instruction in using their augmentative communication systems. They also participate in traditional activities like fishing, horseback riding, swimming and sports. Activities such as talent shows are geared to help children use their systems in fun and creative ways.

Contact: Tracy Kovach, The Children's Hospital, 8030, 1056 East 19th Avenue, Denver, CO 80218, (303) 861-6800.



Camp Echo Aquatic Camp

East Lempster, New Hampshire

Camp Echo is an overnight camp for boys ages 9 to 16 who have one or more limb deficiencies and/or mobility impairment. Enrollment is limited to 10 spaces in each of the two-week sessions. The camp is designed to teach water activities, including swimming, sailing, canoeing and motor boat sports such as water skiing, knee boarding and tubing. Also included is a four-day wilderness canoe trip to northern Maine. Adaptive aquatic techniques utilize a "ski boom" for water skiing and knee boarding and a sit-ski for campers who require support to stand.

The camp cannot provide attendants for boys who need help with personal care, but it does accept boys in wheelchairs if they can function independently. Medical supervision is available 24 hours a day. A one-to-one staff to camper ratio is available when necessary.

Contact: Don Allen, M.D., Camp Director, P.O. Box 36, Lempster, NH 03605, (603) 446-7819 or Vermont Handicapped Ski & Sports Assoc., P.O. Box 261, Brownsville, VT 05037, (802) 484-3525.

Cedar Haven Summer Prog.

West Bend, Wisconsin

The Cedar Haven Summer Program is designed for children with special physical, emotional and educational needs in the West Bend area. More than 60 infants and children with cerebral palsy, developmental delays, learning disabilities and mental retardation attend the nine-week program. Each child is evaluated prior to admission, insurance or alternative funding is verified, and scheduling for their appropriate therapy sessions and a county grant-funded recreational component is designed to fit their needs.

Physical, occupational and speech therapy sessions are available. Games, crafts, music therapy and weekly swimming sessions make up the recreational component of the summer program at Cedar Haven.

The three requirements for enrollment are: The child must be between the ages of 0 and 13 years old, require one or more of the specific therapies (physical, occupational and speech) and have a physician's order. Enrollment is limited so early registration is suggested.

Contact: James D. Aubert, Cedar Haven Rehabilitation Agency, 5595 Hwy Z, West Bend, WI 53095, (414) 334-1486, (414) 276-4370.



BEST COPY AVAILABLE

Home Beach

by Deborah R. Stachkunas

When I was growing up, my mom would tell us that we were going on a vacation to "Home Beach." This meant that there would not be a car trip to a vacation spot but that we would have a special time just being at home. We would run under the sprinklers or pretend to lie on the beach. She might even move lunch outside like a beach picnic.

During the past winter, I was browsing through a catalog and stumbled upon the White Tower section. This concept, developed by Ad Verheul at the Hartenburg Institute, involves designing and constructing "dynamically reacting environments for multisensory stimulation." These custom-built physical environments include the following types of sensory stimulating options: tactile wall boards, sniff boxes, switches, special effects projectors, fiber optics, bubble columns and sound effects. Although this concept is quite fascinating, there were several obstacles to developing a White Tower Room in the school environment where I was teaching. We would need a permanent location for this White Tower Room outside the classroom, but empty rooms are always in demand in growing elementary schools. And, during a year of cutbacks, funding was a major issue.

What happened on a hot day in June was a merger of these two concepts — Home Beach and White Tower. We had a beach party at River Oaks Elementary School at the "River Oaks Private Beach." Field trips were quite a headache with my particular group of students due to special transportation needs, a lack of volunteers and health conditions which were easily aggravated by the heat and pollen count. Although a permanent site was not available within the school to set up a White Tower Room, the gym was available for the day by simply signing up in the office. We were going to take this trip without transportation requisition forms, permission slips, a hot bus or an annoying pollen count. We would be taking a trip to Home Beach, in a manner of speaking.

As the weeks went by, the idea blossomed into a

major event. We sent special beach party invitations home with the students to welcome their parents and siblings to the party. The afternoon before the party, the gym was transformed into the River Oaks Private Beach. Several blue mats were transformed into an ocean complete with floats and a switch-activated surf. The beachfront was extensive. It was possible to play in the sand or water table. For those who enjoy strolling down the boardwalk, ours was a musical Footnotes Piano. Since most beaches have artists, we had an art corner where the students could air brush beach stencil pictures using a ColorBlaster™.

The beach stimulated the senses of all adults and children who entered. The children could activate a pressure switch to hear the ocean roar and the sounds of sea gulls. The piano boardwalk could be activated by walking or rolling on it. The children could gaze at colorful sailboats and fish nets while lying in inner tubes (to provide some vestibular stimulation in a supported position) or sitting in the relaxed comfort of bath chairs, which were great substitutes for lounge chairs.

The water and sand tables provided opportunities for varying degrees of tactile stimulation. Although bathing suits were not permitted, everyone wore beach apparel — shorts, T-shirts, cut-off jeans, sundresses, etc.

Of course, we could not forget the "tunes." Our primary music selection was naturally *The Beach Boys Greatest Hits*. The music was upbeat and quickly put all the adults — parents and staff — into the party spirit. Party On!

The beach was designed to contain elements to motivate all of the students, regardless of their functioning level. Each student could have an impact on some element of the beach as well as obtain enjoyment and satisfaction for their efforts.

A staff member performed the role of roving beach photographer. We used a Polaroid™ camera and displayed the pictures on an art easel as they were developing. It is

continued on page 30



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Includes illustrated instruction manual that shows how to use seat in any car, van or bus.

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Seat Depth	12.5"
Seat Width (at front)	15.5"
Seat Width (at back)	14"
Back Height	28"
Weight Capacity	20 to 102 lbs.
Total Weight	11 lbs.

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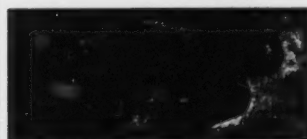
COLUMBIA MEDICAL MFG. CORP.
P.O. Box 633
Pacific Palisades, CA 90272
(310) 454-6612

HOME BEACH MATERIALS

BEACH SIMULATION	BASIC EQUIPMENT	OPTIONAL EXTRAS
Water	Blue gym mats; Inner tubes; Beach floats	Put up pictures of sailboats or fish
Beachfront	Sand and water tables; Lounge chairs	Beach towels; Seashells
Boardwalk	Footnotes Piano pressure- activated music mat	Switch-activated lights or lanterns
Art Arena	ColorBlaster™; Spin art	Sand painting; Sidewalk artist
Ocean	Switch-activated tape recorder w/ocean sounds	Extra tape recorders with various sounds: birds, whales, boats
Roving Photographer	Polaroid™ camera	Camcorder
Beach Fun	Frisbees; Beach balls; VELCRO™ catch mitts; Scooter boards	Roller skates; Roller blades

SAMPLE FLOOR PLAN

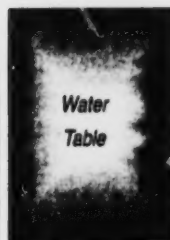
Beach pictures on wall.



Blue mat with inner tubes
and rafts.



Art Arena.



Open area for scooter boarding
or roller skating.



Blue mat with beach balls, boats and seashells.

Fish
nets
on
wall.

continued from page 28

amazing how attentive the students are to Polaroid™ pictures. The memory of the event is still fresh in their minds when they view the picture. Both the staff and students were instantly gratified with the visual memory of the event.

We chose to take our trip in the morning of an early release day. The children had approximately two hours at the beach, then returned to the classroom for a special beach lunch. While the students were playing at the beach, a staff member, assisted by two of our buddies from the fourth grade, assembled the special lunch. The chosen foods lent themselves easily to our varied dietary and oral motor needs. The foods were served cold or were microwavable so we did not need access to the school kitchen. The children enjoyed fish sticks, stuffed clams, cole slaw, chips, veggies, chilled popcorn shrimp, watermelon, fruit shakes and ice cream pie for dessert. As a special treat, we invited buddies from the fourth grade to share our dessert.

After lunch, the children either went home with their parents or boarded the bus to return home. Timing can mean the difference between a fun activity and overstimulation leading to sensory overload. Holding the beach party on a half-day provided us with a suitable time frame — the children had to be ready to leave at a specific time. Since the children leave two hours before the staff on early release days, we had plenty of time to return the beach to a gym after the students left. Clean-up, therefore, did not infringe upon exploration time.

Funding for this event was not an issue. Most of the equipment we used was already part of our classroom stock. The pictures used to create the beach atmosphere were taken from wallpaper sample books. Since we would be preparing lunch for both the students and their families, each family was asked to send in \$4.50 to cover the cost of the beach food. The extra lounge chairs, towels, beach balls, etc. were borrowed from staff members for the day. (See *Home Beach Materials* for a list of suggested equipment.)

The River Oaks Private Beach Party was an awesome success. The staff and parents have already decided this should be an annual event. One of the unexpected rewards of the event was the change in attitude of the support staff in the building. They were mesmerized by the children's actions on the beach. Many times these individuals only see the children in their wheelchairs, traveling quietly or not so calmly throughout the school. Their quiet observations of the students freely exploring the beach activities gave them a little insight into who the children really are. EP

Deborah R. Stachkunas is a special education teacher and a single parent. She lives in Dale City, Va., with her children Thomas, 16, and Trae, 4 months. Her daughter, Jacqueline, passed away last April of medical complications associated with 18q-. Both Thomas, who has cerebral palsy, and Jacqueline, were adopted and Trae is currently in long-term foster care with Stachkunas.

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Accessible Theme Parks

The following is a list of some of the more popular theme parks in the U.S. and information on their accessibility to visitors with disabilities. In most cases, parks have a limited number of wheelchairs available for rental on a first-come, first-served basis. Most park personnel can offer information and assistance but are not trained to assist guests with disabilities and therefore are not allowed to help with boarding or disembarking from rides. Many parks offer accessibility guides and recommend that guests with disabilities be accompanied by someone who can assist them while visiting the park.

- ▼ = Accessible Restrooms
- ☎ = Accessible Telephones
- ⬆ = First Aid
- ☞ = Guide Dogs Allowed
- ◆ = Wheelchair Accessible Parking
- \$ = Manual/Electric Wheelchair Rental

Busch Gardens Dark Continent

P.O. Box 9158
Tampa Bay, FL 33674
(813) 987-5000
For Explorers With Special Needs brochure outlines park accessibility and policy.
▼ + ☎ + ⬆
\$ = \$4/manual + \$1 deposit
\$25/electric carts + \$5 deposit

Busch Gardens The Old Country

One Busch Gardens Blvd.
P.O. Box 8785
Williamsburg, VA 23187
(804) 253-3350
▼ + ☎ + ⬆
\$ = \$5/manual; \$25 electric

Disneyland

c/o Information
1313 Harbor Blvd.
Anaheim, CA 92803
(714) 999-4565
(714) 999-4569 (TDD)
TDDs; complimentary cassette tapes and portable tape player for guests with hearing impairments; *The Disneyland Disabled Guest Guide* details park accessibility and policy.
▼ + ☎ + ⬆
\$ = \$5/manual + \$20 deposit

Oceans of Fun/ Worlds of Fun

4545 Worlds of Fun Ave.
Kansas City, MO 64161
(816) 454-4545, Ext. 8000
Attraction accessibility and park policy guide available at Guest Relations.
▼ + ☎ + ⬆ + ◆ (Both parks)
\$ = \$7/manual
\$12.50/electric (half-day)
\$25/electric (full day)

Sea World

7007 Sea World Dr.
Orlando, FL 32821
(407) 351-3600
All stadium shows and exhibits are wheelchair accessible.
▼ + ☎ + ⬆
\$ = \$5/manual
\$25/electric

Six Flags Great Adventure

Route 537
Jackson, NJ 08527
(908) 928-2000
TDDs and phones with amplifier buttons available for people with hearing impairments; *Guest Accessibility Guide Book* details park accessibility and policy.
▼ + ☎ + ⬆ + ◆
\$ = free/manual

Six Flags Great America

P.O. Box 1776
Gurnee, IL 60031
(708) 249-1776
Free admission to guests with permanent mobility impairments; reduced admission (\$14) to guests with other disabilities; *Accessibility Brochure* available.
▼ + ☎ + ⬆
\$ = \$7/manual + \$10 deposit
\$30/electric + \$10 deposit

Six Flags Magic Mountain

Attn: Public Relations
P.O. Box 5500
Valencia, CA 91385
(805) 255-4100
Reserved seating available for guests in wheelchairs at all theaters and show venues; *Handicap Guide* available detailing ride accessibility and park policy at Guest Relations.
▼ + ☎ + ⬆
\$ = \$6 with valid ID/manual & electric

Six Flags Over Georgia

Attn: Public Relations
P.O. Box 43187
Atlanta, GA 30378
(404) 739-3450
Reduced admission available, based on individual limitations; *Disabled Guest's Guide* details park accessibility and policy.
▼ + ☎ + ⬆
\$ = free/manual
\$25/electric

Six Flags Over Mid-America

P.O. Box 60
Eureka, MO 63025
(314) 938-5300/4805 (TDD)
Accessibility Guide available.
▼ + ☎ + ⬆ + ◆
\$ = free/manual + \$20 deposit or credit card

Six Flags Over Texas

P.O. Box 90191
Arlington, TX 76004-0191
(817) 640-8900
A Guide for Handicapped Guests pamphlet available.
▼ + ☎ + ⬆
\$ = \$6/manual; \$28/electric

Universal Studios, Fla.

Guest Relations
1000 Universal Studios Plaza
Orlando, FL 32819
(407) 363-8000/8265 (TDD)
Wheelchair-accessible indoor dining and shopping; TDD at Guest Relations; audio cassettes; integrated show and ride seating; *Studio Guide For the Disabled Guest* details park accessibility.
▼ + ☎ + ⬆ + ◆
\$ = \$5/manual; \$25/electric

Universal Studios, Hollywood

100 Universal City Plaza
Universal City, CA 91608
(818) 622-3801/8559 (TDD)
Temporary handicap parking passes available for rental cars; wheelchair-accessible water fountains, shopping and dining; Audio-Assist Units available for guests with hearing impairments; *Disabled Guest Guide* details park accessibility and policy.
▼ + ☎ + ⬆ + ◆
\$ = \$3/manual (18" and 20")

Walt Disney World

P.O. Box 10,000
Lake Buena Vista, FL 32830
(407) 824-4321
Special-Lift equipment buses; TDDs; amplified handsets; free use of cassette tapes and portable tape players for guests with hearing impairments; some attractions offer personal translator units to amplify audio; *The Walt Disney World Disabled Guests Guide Book* details Disney's attraction accessibility and park policy.
▼ + ☎ + ⬆ + ◆
\$ = \$5/manual + \$1 deposit
\$25/electric + \$20 deposit (Magic Kingdom and Epcot Center)



Fun in the Florida sun at Busch Gardens Dark Continent.

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•Florida

Action Mobility
1925 10th Ave. No.
Lake Worth, FL 33461
(407) 582-6500
(800) 432-1459 in FL

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•Georgia

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1543 15th Street
Augusta, GA 30901
(800) 637-1378

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•Indiana

Alternative Mobility
28244 Clay Street
Elkhart, IN 46517
(219) 293-0367

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Forward Motions, Inc.
214 Valley Street
Dayton, OH 45404
(513) 222-5001

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•Kentucky

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Full-size/Mini-Van modifications, new used, lifts, dropfloor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

•New Jersey

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Farmingdale, NJ 07072
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•Texas

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EQUIPMENT DEALERS

•Alabama

Alabama Medical Services, Inc.
4320 Narrow Lane Rd.
Montgomery, AL 36116
(205) 284-4499

•California

Rehab Specialists, Inc.
2557 Wyandotte Street
Mt. View, CA 94043
(415) 965-8282

Rehab Specialists specializes in all phases of custom mobility. We are an authorized Chek Marc Repair Center and Quickie Sports Center. Please call, write or fax for free evaluation or for more information. Our fax number is: (415) 966-8108

Rehab Specialists, Inc.
446 Westridge Drive
Watsonville, CA 95076
(408) 724-5544

Rehab Specialists specializes in all phases of custom mobility. We are an authorized Chek Marc Repair Center and Quickie Sports Center. Please call, write or fax for free evaluation or for more information. Our fax number is: (408) 724-3334

Wheelchair House of California
6307 De Soto Ave., Suite E
Woodland Hills, CA 91367
(818) 713-1278

•Florida

Alabama Medical Services, Inc.
4320 Narrow Lane Rd.
Montgomery, AL 36116
(205) 284-4499

•Illinois

Fitzsimmons Surgical Supply
2747 West 95th
Evergreen Park, IL 60642
(312) 881-8700

•Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

•New Jersey

Marathon Medical Equipment
308 Talmadge Road
Edison, NJ 08817
(908) 287-4255
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•New York

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Lubbock, TX 79423
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Wheelchair Accessible National Parks

This directory includes national parks with wheelchair access to campsites, restrooms and visitor centers. Parks marked with an asterisk(*) have at least one self-guiding tour or trail.

A more comprehensive list is available from the National Park Service, U.S. Department of the Interior, Washington, D.C. 20013-7127, (202) 343-3676, (202) 343-3679 (TDD).

ALASKA

**Denali National Park and Preserve*
Thea Nordling
P.O. Box 9
Denali N.P., AK 99755
(907) 683-2294
(907) 271-2716 (TDD)

ARIZONA

**Grand Canyon Nat'l Park*
Special Pop. Coordinator
P.O. Box 129
Grand Canyon, AZ 86023
(602) 638-7888/7772 (TDD)
(Accessibility guide available)

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Gail Sears
P.O. Box 1860
Hot Springs, AR 71902
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P.O. Box 579
Death Valley, CA 92328
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Estes Park, CO 80517
(303) 586-2371, ext. 206
(303) 586-8506 (TDD)

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**Everglades National Park*
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(305) 247-6211 (Voice/ TDD)

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**Glacier National Park*
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West Glacier, MT 59936
(406) 888-5441/5790 (TDD)

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**Great Basin National Park*
Accessibility Coordinator
Baker, NV 89311
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601 Nevada Highway
Boulder City, NV 89005
(702) 293-8920

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**Fire Island Nat'l Seashore*
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Patchogue, NY 11772
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**Blue Ridge Parkway*
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Asheville, NC 28801
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**Chickasaw National Recreation Area*
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Sulphur, OK 73086
(405) 622-3165

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**Crater Lake National Park*
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P.O. Box 7
Crater Lake, OR 97604
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**Wind Cave National Park*
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(605) 745-4600

TENNESSEE

**Big South Fork National River and Recreation Area*
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Rt. 3, Box 401
Oneida, TN 37841
(615) 569-9778

**Great Smoky Mountains National Park*
Gene Cox
107 Park Headquarters Rd.
Gatlinburg, TN 37738
(615) 436-1200

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**Big Bend National Park*
Jeff Selleck
Big Bend National Park, TX 79834
(915) 477-2251
(915) 477-2370 (TDD)

**Padre Island National Seashore*
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Corpus Christi, TX 78418-5597
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**Arches National Park*
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P.O. Box 907
Moab, UT 84532
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**Bryce Canyon Nat'l Park*
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Bryce Canyon, UT 84717
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**Zion National Park*
Dave Karaszewski
Springdale, UT 84767-1099
(801) 772-3256

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**Shenandoah National Park*
Deanne Adams
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Luray, VA 22835
(703) 999-2243

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**Olympic National Park*
Special Pop. Coordinator
600 E. Park Ave.
Port Angeles, WA 98362
(206) 452-4501

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**St. Croix and Lower St. Croix National Scenic Riverways*
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P.O. Box 708
St. Croix Falls, WI 54024
(715) 483-3284

WYOMING

**Grand Teton Nat'l Park*
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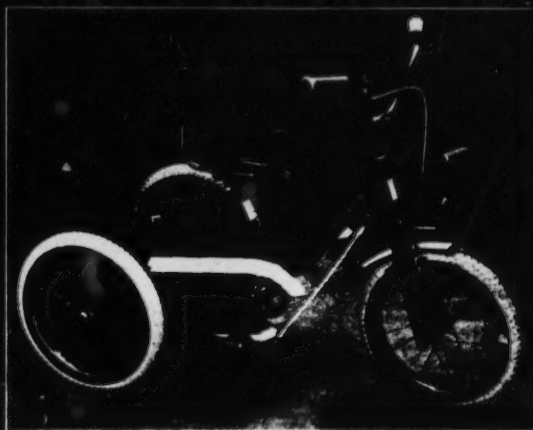
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Aquatics

Beach Wheels, Inc.
1555 Shadowlawn Dr.
Naples, FL 33942
(813) 775-1078

Baseball

Challenger Baseball
Little League Baseball
Headquarters
P.O. Box 3485
Williamsport, PA 17701
(717) 326-1921

Basketball

National Wheelchair Basketball Association
Stan Labanowich
Commissioner
University of Kentucky
110 Seaton Building
Lexington, KY 40506
(606) 257-1623

Bowling

American Wheelchair Bowling Association
Walter Roy, Exec. Dir.
3620 Tamarack Dr.
Redding, CA 96003
(916) 241-6297

Camping

Access: Camping
P.O. Box 356
Malverne, NY 11565-0356
(516) 887-5684

American Camping Association
5000 State Road 67 N
Martinsville, IN 46151
(317) 342-8456

Wilderness Inquiry
1313 Fifth Street SE
Box 84
Minneapolis, MN 55414
(612) 379-3858

Wilderness on Wheels
7125 W. Jefferson Ave., #155
Lakewood, CO 80235
(303) 988-2212

Canoeing

Canadian Recreational Canoeing Association
1029 Hyde Park Rd.
Suite 5
Hyde Park, ON
Canada N0M 1Z0
(519) 473-2109

Cooperative Wilderness Handicapped Outdoor Group (C.W. Hog)
Jim Wise
Director
Idaho State University
Box 8118
Pocatello, ID 83209
(208) 236-3912

S'PLORE — Special Populations Learning Outdoor Recreation & Education
27 West 3300 S.
Salt Lake City, UT 84115
(801) 484-4128

Fishing

Adaptive Physical Education & Recreation
Frederico Ceccoti
PO Box 269
Alfred I. duPont Institute
Wilmington, DE 19899
(302) 651-4000

Football

Recreation & Athletics
Brad Hedrick
136 Rehabilitation Ed. Ctr.
1207 S. Oak Street
Champaign, IL 61820
(217) 333-4606

Gardening

American Horticultural Therapy Association
362A Christopher Ave.
Gaithersburg, MD 20879
(301) 948-3010

General Recreation

American Alliance for Health, Physical Education, Recreation and Dance
1900 Association Dr.
Reston, VA 22091
(703) 476-3400

Intl. Center on Special Rec.
362 Koser Ave.
Iowa City, IA 52246-3038
(319) 337-7578
Info, referral center w/special recreation access library, publications and quarterly newsletters. Parent, teacher hotline.

National Therapeutic Recreation Society
3101 Park Center Dr.
Alexandria, VA 22302
(703) 820-4940

Horseback Riding

North American Riding for the Handicapped Assn.
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Denver, CO 80233
(800) 452-RIDE

Winslow Therapeutic Riding Unlimited
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Warwich, NY 10990
(914) 986-6686

Ice Skating

Skating Association for Blind and Handicapped
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Amhurst, NY 14226
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Motorcycling

Wheelchair Motorcycle Assn.
Dr. Eli Factor
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Brockton, MA 02401
(508) 583-8614

Music Therapy

Natl. Assn. for Music Therapy
8455 Colesville Rd., #930
Silver Spring, MD 20910
(301) 589-3300

Sailing

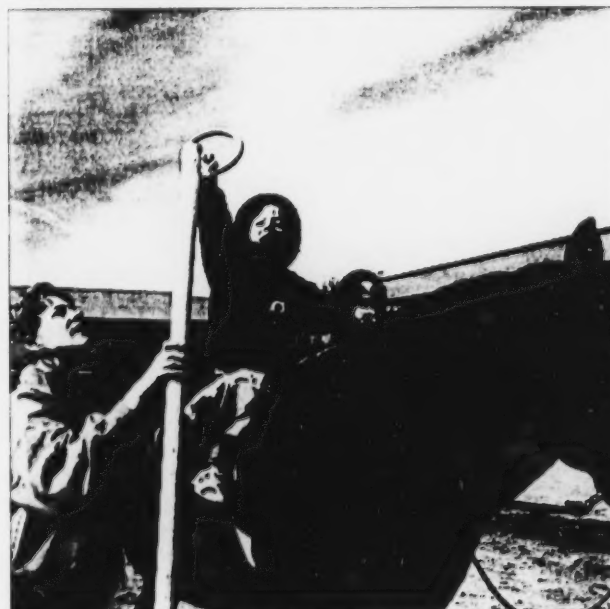
National Ocean Access Project (NOAP)
P.O. Box 33141, Farragut Sta.
Washington, DC 20033
(301) 217-9843

Scouting

Boy Scouts of America
Scouting for the Handicapped
1325 W. Walnut Hill Ln.
P.O. Box 152079
Irving, TX 75015-2079
(214) 580-2000

Camp Fire Boys & Girls
Emerson Goodwin
4601 Madison Ave.
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Girl Scouts of the USA
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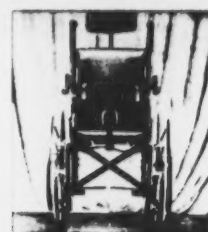
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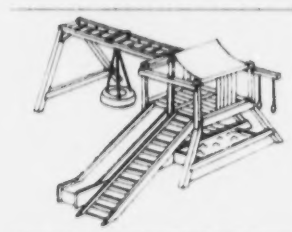
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DIRECTORY OF ADVERTISERS

Advertiser	Page#	Advertiser	Page#
Aquatic Therapy	23	Jesana	43
ASHA	25	Kid Kart	9
Beebop	25	Kinder Wagen	50
Berkshire	67	League School	68
BHC - JA Preston	back cover	Martha Lloyd	65
Braun Corporation	38, 39	Mobility Tech	23
Bruno	15	Mulholland	45, 46
Charles C. Thomas	61	N/R Labs	18
Chrysler P-CAP	12	Ortho-Kinetics	47
CindyLift	44	Otto Booh	47
Columbia Medical	29, 31	Phonic Ear	10
Consumer Care	18	Plum Enterprises	1
Convaid Products	7	Prime Engineering	48
Crow River	11	Quickie	5
Danmar	31	Racing Strollers	31
EP Press	inside back cover	Rifton	44
Equipment Shop	13	Roleez	35
Estate Planning	23	Rollins Healthcare	25
Flaghouse	25	Ross Labs	73, 75
Ford	2	Scott Designs	48
Hacienda de los Angeles	68	Sign Enhancers	13
Havench-Ortho	13	Snug Seat	8
HDIS	13	Sportime	19
Heartspring	69	St. John's Villa	68
HMS	68	Taylor Made	43
Hoening Mobility	35	Toto Kiki, USA	19
Innovative Products	15	TRIAD	35
Jay Medical	inside front cover	Woodbury Products	23

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329

RESOURCE SECTION

continued from page 36

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52 Association for the Handicapped
Allan Weinberg, Exec. Dir.
350 Fifth Avenue, Rm. 7710
New York, NY 10118
(212) 563-2693

Canadian Association for Disabled Skiing
P.O. Box 307
Kimberley, BC
Canada V1A 2Y9
(604) 427-7712

Ski For Light International
3101 Old Highway Eight
Roseville, MN 55113
(612) 633-9250

U.S. Deaf Skiers Assn.
James Stern, Secretary
62 Woodbury Court
Washington Township, NJ
07675
(Mailing address only)

Softball

National Wheelchair Softball Association
Jon Speake
Commissioner
P.O. Box 22478
1616 Todd Court
Minneapolis, MN 55033
(612) 437-1792

Sports (Various)

Braille Sports Foundation
4601 Excelsior Blvd., Ste. 321
St. Louis Park, MO 55416
(612) 920-9363
Publishes *Feeling Sports*, a bi-monthly newsletter; provides leisure, recreation & therapeutic information.

Canadian Wheelchair Sports Association
1600 James Naismith Dr.
Gloucester, ON
Canada K1B 5N4
(613) 748-5685

National Handicapped Sports
451 Hungerford Dr., Ste. 100
Rockville, MD 20850
(301) 217-0960

National Wheelchair Athletic Association
3595 Fountain Blvd., Ste. L1
Colorado Springs, CO 80910
(719) 574-1150

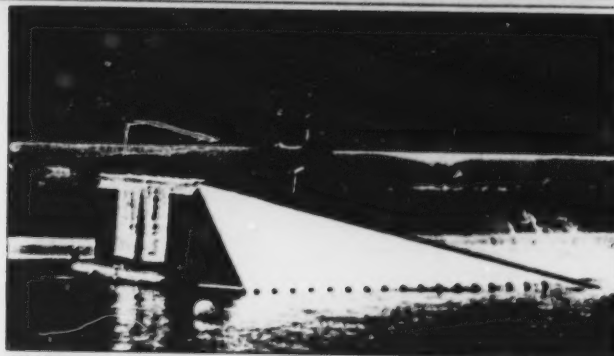
Special Olympics
1350 New York Ave. NW
Suite 500
Washington, DC 20005
(202) 628-3630

U.S. Assn. for Blind Athletes
33 N. Institute St.
Colorado Springs, CO 80903
(719) 630-0422

U.S. Cerebral Palsy Athletic Association
Michael King
Executive Director
3810 W. Northwest Hwy.
Suite 205
Dallas, TX 75220
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(312) 726-4528 (TDD)

National Theater of the Deaf
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Chester, CT 06412
(203) 526-4971
(203) 526-4974 (TDD)

Swimming

Physically Challenged Swimmers of America
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229 Miller St.
Middleboro, MA 02346
(508) 946-1964

Performing Arts Theatre of the Handicapped (PATH)
Bob Cole
President
P.O. Box 3106
Carlsbad, CA 92009
(619) 753-3386

Tennis

National Foundation of Wheelchair Tennis
Brad Parks, President
940 Calle Amanecer
Suite B
San Clemente, CA 92673
(714) 361-6811

Very Special Arts
1331 F Street NW
Suite 800
Washington, DC 20004
(202) 628-2800
(202) 737-0645 (TDD)

Track & Field

Achilles Track Club
Dick Traum
9 East 89th Street
New York, NY 10128
(212) 967-9300

International Wheelchair Road Racers Club
Joseph M. Dowling
President
30 Myano Lane
Stamford, CT 06902
(203) 967-2231

Water Skiing

American Water Ski Assn.
Jim Grew
799 Overlook Dr.
Winter Haven, FL 33884
(813) 324-4341

Weightlifting

U.S. Wheelchair Weightlifting Federation
Bill Hens
39 Michael Place
Levittown, PA 19057
(215) 945-1964



Wheelchair racing with Special Olympics; outdoor wheeling with Wilderness on Wheels.

Photo courtesy of Special Olympics

Photo by Douglas Anderson, courtesy of Wilderness on Wheels

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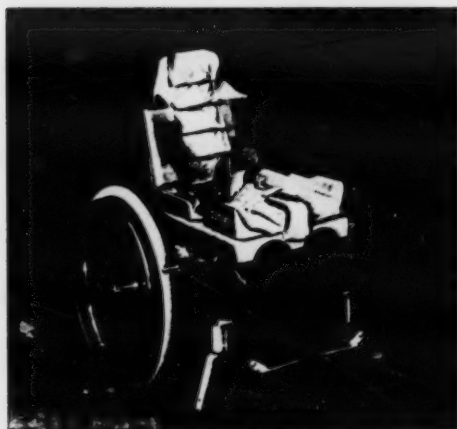
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Selecting a Seating System

by Elaine Trefler

It is critical that children be sitting as well as possible before considering their potential for access to other technologies, such as mobility devices. Because the child usually controls other technology (e.g. adapted toys, communication devices, computers) from the wheelchair, selection of the seating system for the wheelchair is most important.

The process of assessing a child for a seating system must include all people who interact with the child on a daily basis (i.e., family members, peers, teachers, teacher assistants, therapists, etc.) because these people know the level of function expected of the child. Physical and occupational therapists, rehabilitation technology suppliers, and rehabilitation engineers can be especially helpful in translating the child's functional ability and positioning needs into technological solutions. Following their evaluation, the seating team will make recommendations to the family regarding the type of system, the support contours, and the components appropriate for a given child.

The assessment results will indicate the technology that will best meet the child's needs. As there are so many choices of seating systems and wheelchairs, and because prices can range from hundreds to thousands of dollars for each component, the technology selection must be made carefully. Mistakes are costly, and children may be forced to use inappropriate technology for years until new financing is found.

In selecting the seating system, the team will look at the physical, psychosocial, economic, growth, and height considerations that will affect the child.

Physical considerations

Children with physical disabilities have somewhat predictable physical conditions.

- Those with spinal cord injuries have no or partial sensation or muscle activity below the level of their injury. If the spinal cord is damaged just above the waist, then the legs and lower trunk are paralyzed and there is no feeling or voluntary movement below the site of the

damage. If the injury is to the neck, the arms and trunk also experience motor and sensory loss. Therefore, the seating system should be selected for its ability to relieve pressure, thus preventing skin breakdowns from occurring, and for its ability to provide sufficient support to ensure a stable midline posture.

- Children with spina bifida, a congenital lesion of the spinal cord, have no sensation or muscle ability below the level of their spinal deformity; often, they have very thin skin over the areas on the back where surgery has been performed to repair the birth defect. Again, the seating system must prevent skin breakdown. Being seated on a good quality cushion or foam helps prevent injury under the buttocks; custom contouring is often needed to accommodate the abnormal curvature of the spine. Alternate floor-level mobility, such as caster carts or hand-propelled mobility devices, help prevent injury to the legs and heels that occur as the children pull themselves around on the floor. Children with spina bifida or spinal cord injuries are also incontinent, so seating materials must be soil-resistant until a routine is established to manage bowel and bladder care.

- Children with cerebral palsy have problems with muscle tone and/or muscle coordination. If they have too much tone, their bodies will be stiff. Too little tone



Track Mounted Adaptive Seating and Positioning Components for wheelchairs by Mulholland.

results in floppy "rag doll" postures. Those having spastic cerebral palsy most often have too little tone in their trunks and too much tone in their arms. They have difficulty sitting and using their arms or hands. For them, seating must be firm with sufficient trunk support so they will be able to move without fear. Children with athetoid

continued on page 44

ARCH

ARCH Regional Training Institutes

Summer 1993

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**Midwest
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Bloomington, Minnesota
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**West Coast
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Seattle, Washington
August 12-13, 1993

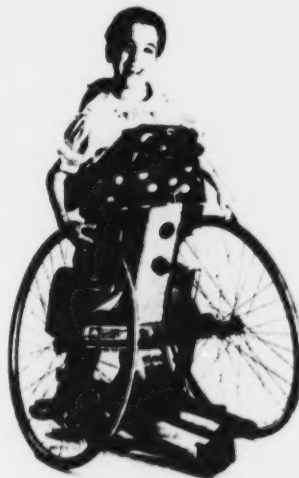
The ARCH National Resource Center for Crisis Nurseries and Respite Care Services is proud to announce the ARCH Regional Training Institutes for the summer of 1993. These Institutes will focus on effective community collaboration. Participants will have the opportunity to work with Arthur Himmelman, a nationally recognized expert in the field of community collaboration.

Given the economic reality of federal, state and local governments, effective community-based organizations will be exchanging information, altering activities, sharing resources and forming partnerships to better serve their communities. Participants will master practical skills which will enhance their ability to create meaningful partnerships within the community — a critical skill for organizational survival in the 1990s!

For more information, contact the ARCH National Resource Center, Chapel Hill Training-Outreach Project, 800 Eastowne Dr., Chapel Hill, N.C. 27514, (919) 490-5577, (800) 473-1727.

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continued from page 42

cerebral palsy generally have too little tone most of the time, with sudden bursts of too much tone.

In these cases, the seating system should offer firm support and should restrict some of the extra movement. These abnormal tone patterns vary in degree from mild to severe and affect the amount of physical control the child has to

perform functional activities.

Children with cerebral palsy also must deal with primitive motor patterns that resolve at an early age in children developing in a more typical fashion. ...

Not every child exhibits every reflex, and the intensity will vary by child. A teacher and family can consult with the child's clinicians to determine management procedures that will minimize the effects of these reflexes on the child's posture. These reflex patterns, as might be assumed, also affect a child's ability to activate a switch or participate in any activity that requires body motion. ...

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will allow the child to focus attention on classroom activities. It will also provide an added security and stability that will enable the child to use his or her hands for eating, activating a communication device, using a computer, manipulating classroom materials, or playing. In selecting technology for young children, it is important to remember that one device can never meet all the needs of an active, growing child. Besides the primary seating system, there are other devices that can provide access to many activities.

This material was excerpted from *Technology in the Classroom: Applications and Strategies for the Education of Children with Severe Disabilities, Positioning, Access, and Mobility Module*, one of four in a series of modules from the Technology in the Classroom kit, available only from the American Speech-Language-Hearing Association. The purpose of this module is to provide information about assistive technology that will be helpful in serving children with disabilities.

This 57-page manual provides basic principles regarding a child's positioning and mobility needs and the use of assistive technology to meet those needs. A suggested format for assessing and providing technology that will help a child access technical devices is provided, as is a discussion about using technology for environmental control.

Along with the overview and basic principles, orthopedic conditions, sensory status, functional skills, alternative equipment, psychosocial considerations and economic issues are discussed. The seven appendices provide resources for the technology, funding options, fact sheets and a case study.

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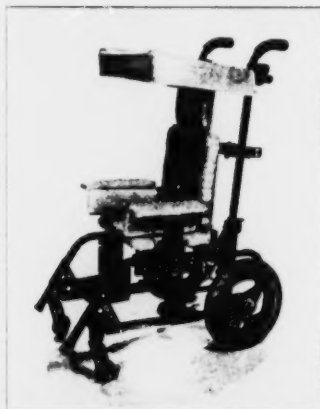
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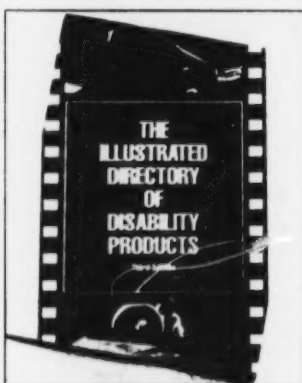
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PRESIDENT'S MESSAGE

by Diana Cuthbertson

Parents' Voices Heard on the Hill

Parents' voices are being heard at all levels this spring as we participate in health and education reform and as we work to make our own children's programs more effective. Working with the Education Task Force of the Consortium of Citizens with Disabilities (CDD) in Washington, D.C., parents were able to get language into the new administration's national program for education reform, Goals 2000: Educate America Act (EAA). NPND, working with its advocacy partners, made a major contribution with the inclusion of students with disabilities in the bill's definition of "all students."

This is a clear statement that students with disabilities should participate in this country's school reform activities and are intended to benefit from this bill. As this issue goes to press, HR 1804 is about to be reported out of committee. For a copy of HR 1804, write Document Room, B-18, Ford House Office Building, Washington, D.C. 20510 to find out how children with disabilities fit into the national goals.

This work at the national level has very clear implications for parents as they consider their role in making this act a reality. Parents will need to become familiar with the major trends in school reform. One option is to keep our separate and specialized educational services and settings, including separate classrooms and schools, to accommodate the range of individual and unique needs of students with disabilities.

A second option is inclusive or heterogeneous education, which

represents the philosophy that all students, regardless of the challenges presented by their educational needs, should be educated with same-age peers in their neighborhood schools. However, this option does not require the blending of general and special education programs.

A third option, the unified system, creates an educational system that is based on the principle that each student represents a unique combination of abilities and educational needs and may require individual assistance during the school year to achieve important outcomes. There is a blending of resources and schools are organized around services, not programs.

As we work toward school reform, we must: (1) have a clear vision and mission for education that includes all students; (2) establish a system of accountability for all education programs; (3) create an organization that supports the mission of restructuring; (4) change what schools teach and how they teach it; and (5) create supports for staff development and staff renewal (Center for Policy Options in Special Education, University of Maryland).

The leadership of the National Parent Network on Disabilities wants to examine and participate in all aspects of educational reform and school restructuring while assuring that all protections of the Individuals with Disabilities Education Act (IDEA) are kept intact.

Parents on the local level may be participating in reform activities at your neighborhood schools or through district-wide planning. Have you attended a Board of Education meeting lately to find out if reform efforts are underway? Do you know what efforts your State Department of Education is engaged in concerning education reform that includes students with disabilities? Make your voice heard.

CONTENTS:

President's Message	51
Executive Director's Report	52
Marti Gentili Brought Out Our Best	52
Legislative Update	53
Promoting Recreation & Leisure	54

EXECUTIVE DIRECTOR'S REPORT

by Patricia McGill Smith

As many of you know, NPND recently received a four-month planning grant from the DeWitt Wallace-Reader's Digest Fund. The grant was made as part of the Fund's School/Family Partnership Initiative, which is designed to increase family involvement in the education of their children.

We will work with the State-wide Parent Advocacy Network of New Jersey to develop a plan, "All Children Belong" (ACB), to help parents promote the inclusion of children with disabilities into regular education classes. ACB will do its developmental work in New Jersey. NPND will create a model for local community action teams that will support the inclusion of children with disabilities in regular classrooms. If the planning project proves successful, NPND will seek funding for implementing its program in five additional states.

The arrival of spring in Washington, D.C., is always a colorful, exciting time. As you can see from the *Legislative Update* (page 53), the presence of a new administration has heightened the activity level and excitement here. The Consortium for Citizens with Disabilities (CCD) has been busier than ever.

In addition to the activities described elsewhere in *Networking*, I am now serving, along with Barbara Huff and Alan Bergman, as a co-chairperson for the Children and Family Task Force of CCD. The short-term goal of the task force is to develop legislation that can stand alone or be attached to other legislation that will provide support, most notably cash, for families of children with disabilities.

Approximately 14 states have now introduced or passed such legislation. Longitudinal data from states such as Minnesota and Wisconsin indicates the effectiveness of family

support which places the family in control of how resources are expended. Out-of-home placements go down and the cost per child or family receiving services is lower than in more traditional paradigms of "supporting" families in which professionals decide what families need. The Task Force is moving toward action steps in the near future.

Please take a look at the Family Support coupon below. If you agree with it, fill it out and return it to the national office of NPND.

Our president, Diana Cuthbertson, made a presentation to the OSERS Leadership Conference held here in D.C. in late April. Her remarks on inclusive schools were well received. She made the voice of parents heard and respected. She represented the NPND membership very well.

NPND members representing the western U.S. recently worked with Larry Searcy, NPND director of programs and government relations, to review the administration's Goals 2000: Educate America Act. The resulting document was approved by the NPND Executive Committee and forwarded to Congressional staff working on the bill.

Several of our comments were adopted in the final version of the House bill. Most notably, the inclusion of DOD schools was at the top of the list. Most importantly, however, this work communicated to Congress the concerns of parents of children with disabilities surrounding all of the upcoming legislative actions that could impact on the education of our children. Congratulations on a job well done!

Marti Gentili Brought Out the Best in All of Us

by Joanne Butts, NPND Vice President

Marti Gentili was someone who dreamed about a national organization for parent training and information centers and parents of individuals with disabilities. Marti was a



Marti Gentili

charter member of the NPND Board Directors and served as our second president. She was a spokesman for families in both Washington, D.C., and her home state of Washington.

Marti was the executive director of Washington PAVE from the time it was first funded in 1981 until her death on Feb. 28, 1993. Marti's vision was always on what could be — not on what was lacking. This was true in all parts of her life — family, community, church and her work. She was gentle, kind, compassionate, funny, tough and so bright and articulate.

She had an uncanny ability to see all sides of an issue or problem. She said it wasn't always a gift — sometimes it felt like a curse because it made decisions difficult. But it was so helpful to those around her, broadening our perspectives and helping us to be less judgmental.

Marti looked at people and saw the best. We accomplished things we might never have thought possible because she believed we could. She rejoiced in our successes. She did not feel diminished or threatened by anyone's accomplishments — she celebrated them. She accepted and appreciated the differences in each person. She thought each person was special and unique, so in talking to her, we felt special and unique.

Marti had many accomplishments. She was a Peace Corps volunteer from 1966 to 1968; a teacher from 1964 to 1968; she wrote a weekly

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newspaper column, *Parent Programs*, for the *Tacoma News Tribune* from 1977 to 1978. She was instrumental in the beginning of PAVE, NPND and the TAPP Project.

Marti was named Professional of the Year in 1982 and was a member of the Washington State Special Education Advisory Council, a former member of the TAPP Select Committee on the Underserved and Underrepresented, appointed to the Commission on Children, Youth and Families and appointed to the Statewide Task Force on Funding of Special Education by the Washington State Special Education Director. Her counsel was sought at all levels; her contributions were invaluable.

Her greatest pride and success was her family — Ken, Julie, Gina and Joanna. She will forever be missed, but her legacy lives on in each one of us, PAVE and NPND.

Legislative Update

By Larry Searcy, NPND Director of Programs and Government Relations

Appropriations

The administration's budget proposal for fiscal year 1994 was released in April. The proposed budget for the Department of Education contains an additional \$393 million to fund Goals 2000: Educate America Act. Special education gains \$22.8 million over 1993. The administration proposed to decrease Chapter 1 funding by \$12.6 million and add that amount to Part B. All in all, the administration claims an increase of \$14 per child served with Part B funds.

Parent Training and Information Centers are recommended for level funding at \$12.4 million. At the time of this writing, this represents a 2.7 percent cut in funding because of inflation. Additionally, PTIs are still not recommended to receive funding to provide the early intervention services for which they were mandated and authorized a few years ago. The Consortium for Citizens with Disabilities (CCD) has recommended PTI

funding to be \$17.6 million for 1994, as has NPND.

Vocational rehabilitation is recommended for a funding level of over \$1.9 billion. The administration's request represents a 3.2 percent increase over 1993. It includes \$10.6 million to support innovative, community-based demonstration supported work projects that target unserved and underserved populations as well as 12 new statewide supported work system change projects. It appears that funds will again be earmarked to provide training to parents and family members of persons receiving vocational rehabilitation services. NPND advocated for and assisted in getting the administration to infuse about \$600,000 into the new Title 8 of the act to provide these services.

All in all, this budget request generally gets rid of small, categorically funded programs and creates large blocks of funds that will be passed along to the states.

Education Reform

The administration's education reform act, Goals 2000: Educate America Act (EAA), surfaced in the middle of April. The act codifies a National Goals Panel and a National Education Standards and Improvement Council. It also provides funding to states that develop plans to revamp their education systems consistent with the six national education goals. These are the same goals we came to know and love in the past administration's America 2000 initiative.

At the time of this writing, the bill's definition of all students includes students with disabilities; DOD schools are covered; IDEA is protected from the granting of waivers; and some 35 other amendments were successfully adopted at the subcommittee level.

NPND has worked closely with the CCD as well as parent leaders around the country to gain improvements in the bill. All in all, the bill is about as good as it's going to get. NPND will track its progress and keep you informed.

National Health Care

The administration's national health care proposal is due to be made public sometime after we go to press. Ira Magaziner, coordinator of Hillary Clinton's Health Care Task Force, characterized some of its anticipated features with human service advocates in early April and again in May.

During a combined four-hour question-and-answer period, he indicated that the proposed plan would cover all citizens regardless of disability and/or "pre-existing conditions" at no additional cost. He also indicated that long-term care, including personal assistance services, would be available through the administration's proposal.

NPND is working closely with Family Voices (a coalition created during the last few months with the specific intent of impacting this legislation in a way benefitting children with disabilities and/or special health care needs) and UCPA to track this legislation. NPND will provide further information concerning the administration's proposed National Health Care Plan when it is available.

Family Support Legislation

Our own Patty Smith recently agreed to serve as a co-chair of the Family Support Task Force of the Consortium for Citizens with Disabilities. In this role, she will help shape and promote legislation that will provide fiscal and other support for families of children with disabilities. Included in the work of this Task Force is the Family Preservation Act, the Children's Mental Health Act and draft legislation known as the Children with Disabilities Support Act. Currently, we have a draft bill available on request. We want to hear from parents and family members nationwide who are in favor of moving forward on Family Support legislation. If you favor such action, please clip, fill out and return the Family Support coupon found on page 52.

We'll keep you posted as these efforts begin to take shape.

Promoting Individualized and Integrated Recreation and Leisure Experience

by Pam Walker, Syracuse University
Center on Human Policy

Recent efforts in the field of developmental disabilities have focused on supporting people in individualized and flexible ways. An individualized approach to recreation and leisure involves moving away from special programs by instead developing the supports that will enable people to participate in regular community programs, activities and settings.

Three strategies related to this include: assisting people in developing and maintaining interests; utilizing community resources; and facilitating social interactions and relationships.

Developing and Maintaining Interests

Interests provide a vehicle through which people get involved in community activities and form connections with other people.

O'Brien and Lyle (1987, p. 35) speak of the importance of interests: "Interests link the personal and the social. They express individual gifts, concerns, and fascinations and call for activities, information and tools . . . Shared interest founds associations. People point to interests when they describe what gives their lives meaning." Over time, people may establish "leisure identities" (McGill, 1987). This entails developing an interest to the extent that it becomes one of the primary defining characteristics of a person. This can help take the focus off the disability as a primary defining characteristic.

Utilizing Community Resources

To promote involvement in regular community recreational activities and settings based on people's interests, it is necessary to be informed about what kinds of places, organizations and activities exist and who goes there, for what purposes, at what times, etc. (Center on Human Policy, 1990; O'Connell, 1990). One needs to

think about where people without disabilities who have similar interests or likes/dislikes spend time.

In cases where certain community activities or resources are insufficient or nonexistent, one could advocate for the development of such resources.

Facilitating Social Interactions and Relationships

Another aspect of assisting people to participate in community activities and settings may be the strategy of "facilitation" or "bridge-building" (Mount, Beeman and Ducharme, 1988). This can be used, in particular, to move beyond physical integration to social integration.

A number of lessons have been learned by people who make such efforts on behalf of people with disabilities (Mount et al., 1988).

- It is best done on an individual basis — one person at a time.
- The personal, local connections of bridge-builders are critical.
- There are no set rules or models to follow; rather bridge-building calls for creativity and flexibility.

Summary

Additional effort must go into helping people with developmental disabilities have integrated recreation and leisure experiences which also provide opportunities for social relationships with people without disabilities and obtain valued roles in the community. Issues related to this include:

- Ensuring that adequate supports are provided for full participation.
- Learning about and from community places and organizations.
- Collaboration of diverse human service agencies, community service agencies and community members is essential to the promotion of maximum opportunities for inclusion (Schleien, Light, McAvoy and Baldwin, 1989).
- Building community coalitions. As integrated recreation/leisure

Update of Membership

Update on the membership of the NPND as of March 27, 1993:

Parent Coalitions — 74 Individual — 211
Parent Groups — 32 Professional — 62
Affiliated Organizations — 33

New Groups

Affiliated Groups

- *Monaco & Assoc.* 501 NE 35th, Topeka, KS 66617, (913) 286-0218.
- *Maryland Infant & Toddlers Program*, 300 W. Lexington St., Suite 304, Baltimore, MD 21201, (410) 333-8100.
- *ARC of Conn.*, 1030 New Britain Ave., #102-B, West Hartford, CT 06110, (203) 953-8335.
- *Cumberland Hospital for Children & Adolescents*, P.O. Box 105, New Kent, VA 23124, (804) 966-2242.
- *Mid-South Regional Resource Center*, University of Kentucky, Human Development Institute, 121 Mineral Industrial Building, Lexington, KY 40506.

Parent Groups

- *ARC of Central Virginia*, 1508 Bedford Ave., Lynchburg, VA 24504, (804) 845-4071.
- *Federation of Families for Children's Mental Health*, 1021 Prince St., Alexandria, VA 22314, (703) 684-7710.
- *Urban Parents Becoming Effective Parents Through Training*, 9950 Fielding, Detroit, MI 48228-1214, (313) 837-1343.

comes to be seen as more of a priority in people's lives by more people (family members, educators, recreationists, residential service providers and community members), children and adults with disabilities will have increased opportunities to enjoy the same range of activities, experiences, roles and relationships as nondisabled community members.

This was prepared by the Research and Training Center on Community Integration with support from the National Institute on Disability and Rehabilitation Research. No endorsement by the U.S. Department of Education of the opinions expressed should be inferred. For more information, write to the author at the Center on Human Policy, 200 Huntington Hall, Syracuse, N.Y. 13244-2340.

For a list of references and select resources, contact NPND, 1600 Prince St., #115, Alexandria, Va. 22314, (703) 684-6763.

Networking is information from the National Parent Network on Disabilities. The Network is a membership organization open to all agencies, organizations, parent centers, parent groups, professionals and all individuals concerned with the quality of life for people with disabilities.

Patricia M. Smith

Executive Director



WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY

by Marilyn Lash, M.S.W. Published by *Exceptional Parent*, in collaboration with the Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center, ©1992 Tufts University. For information about purchasing *When Your Child Goes to School After an Injury*, see ad at right.

The following excerpt is from the chapter *Getting to and from School Safely* by Kim Hesse, M.S.W., Massachusetts Passenger Safety Program, Massachusetts Department of Public Health, with assistance from Susan Larsen, R.P.T., Diane Ricciotti, Deborah Davia Richards, Cynthia Rodgers, M.P.H., Paul Schreiber, M.D., and Karen Bruner Stroup, Ph.D. Edited by M. Lash.

Recommendations for (safety) devices

Many physical and emotional conditions are listed below and followed by devices that may be suitable. These devices all meet applicable federal safety criteria. Some of these devices will not be appropriate for your child. It is important that you discuss each device with your child's caregivers and your child to determine which is best for your situation. Every child is different. If your child's condition is not listed here, it does not mean that there is not a suitable device. Check with the professionals involved in your child's care. Also, talk with other parents

who have children with the same condition as your child. To use these devices and positioning aids correctly, follow all instructions carefully and contact your child's caregivers, your state's highway safety or public health departments, or the manufacturer or distributor. If you want to use a device that is not mentioned here, consult your child's caregivers. Also, ask for the crash test report from the manufacturer. You may need help from your child's care providers or the state highway safety or public health programs to check if the reports are from a reputable crash test laboratory. For manufacturer/distributors' addresses and phone numbers, contact your child's care providers or any of the organizations listed at the end of this (excerpt).

Children with spinal cord and brain injuries, bone fractures, poor balance or impaired strength

Also children with muscular/skeletal conditions, congenital or

degenerative neurological conditions, and developmental disabilities:

- **Infants:** Conventional child safety seats, Swinger Home and Car Bed, Cosco Dream Ride (used horizontal), Evenflo, Dyn-O-Mite.

- **Toddlers and Older Children:** conventional child safety seats, Britax Special Car Seat, Carrie Seat, Columbia Orthopedic Positioning Seat, E-Z-ON Vest, E-Z-ON Modified Vest, Kidster, Snug Seat, Safety Rehab Primary 500 Series and 900 Series Transporter, Ortho Kinetics Travel Chair, Spelcast Child Car Seat, Mulholland Growth Guidance Seating Systems.

Children with emotional/behavioral conditions

- **Infants and toddlers up to 40 lbs.:** conventional child safety seats (convertible seats with five point harness systems work best to restrain children.), Little Cargo Vest.

- **Toddlers and older children:** Booster seat may work, E-Z-ON Vest

continued on page 59

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We recently invited Alliance for Technology Access centers to submit success stories describing individuals or families who have incorporated technology into their lives. This is *Exceptional Parent's* fourth installment of these stories.

In many cases, specific products illustrate the wide variety of technology tools available and represent a few of the many products demonstrated and used at ATA centers.

ATA Scrapbook of Success

Proving intelligence

The Disabled Children's Computer Group (DCCG), the ATA center in Berkeley, Calif., conducts hundreds of family consultations each year. One that stands out was with the family of a three-year-old child with cerebral palsy. K.C. is nonverbal and has extreme spasticity.

It was the family's first experience with computers. They met with Jennifer, a computer resource specialist, and her daughter, Portia, a teenager who also has cerebral palsy. In the first few moments of the appointment, K.C. learned to push the PowerPad, a touch-sensitive alternative input device, and operate a program called *Wheels on the Bus*. It was exciting for his parents to see him do something successfully.

During the appointment, K.C. excited everyone with his ability to work with the computer. Fortunately, we were able to lend them a computer, a PowerPad and an Echo speech synthesizer so they could test the equipment further at home.

They had a little bit of trouble when they got home, so we provided some technical support by phone. We were so pleased when we heard the words of the speech synthesizer saying a line from the *Paper Dolls* program for the PowerPad, "You found the underwear, now where is my T-shirt?"

His parents plan to get a computer now that K.C. has had success using it. Before this there was no

way for him to prove he was smart. K.C.'s parents knew it and the computer helped demonstrate his abilities.

More control, more confidence

Lexi Syme is a fifth-grade student at Big Sky Elementary School in Billings, Mont. Lexi is very outgoing and has a warm personality. During her fourth-grade year at the school, Lexi had an energetic teacher who wanted to see her gain more independence.

Throughout her school career, Lexi had a personal aide who did all of her writing for her. Her teacher



With computers, Lexi is independent and better able to express herself.

wanted to eliminate the intervention of the aide and give Lexi the experience of composing her own work and doing her homework without any help.

Lexi uses a wheelchair for most of her mobility. She has good gross motor use of her hands, but her fine motor skills such as writing are limited, especially when she needs to take notes.

Our goal for assistive technology intervention was to get Lexi to think for herself and do more of her assignments on her own with minimal help from the aide. Our challenge was to help Lexi achieve greater independence using the kinds of simple technology already available in the school.

Through collaboration and

consultation between the school, parents, teacher and PLUK (Parents Let's Unite for Kids — the ATA center in Billings, Mont.), we got an Apple IIGS for Lexi to use in the classroom.

We started out with the 80-column *Magic Slate* program. Using this software, Lexi was able to do her written assignments, her spelling lessons and keep a daily journal like the other students in the fourth grade. For the first time, she had to learn how to use punctuation, capitalization and appropriate grammar. In the process of doing her own writing, Lexi matured rapidly in her composing skills.

This year in fifth grade, Lexi is using the software program *Predict It*. Her writing speed has increased and she is better able to keep up with the volume of written work.

Lexi now has a Macintosh LC computer at home so she can do homework using her *Predict It* program. She feels more in control of her own education and is better able to express herself. She is less dependent on an aide and more confident of her own abilities. Computer access for word processing has provided Lexi with the chance to respond just like her fifth-grade classmates.

Wheels on the Bus and *Paper Dolls* are available from the Early Intervention Program, 1000 Veteran Ave., Room 2310, Los Angeles, Calif. 90024, (310) 825-4821. *Predict It* is available from Don Johnston Developmental Equipment, P.O. Box 639, 1000 N. Rand Rd., Bldg. 115, Wauconda, Ill. 60084, (800) 999-4660. *Magic Slate* is available from Sunburst Communications, 101 Castleton, Pleasantville, N.Y. 10570-3498, (800) 628-8897.

The Alliance for Technology Access (ATA) is a network of community-based technology resource centers dedicated to providing access to the assistive technologies and related services that enable people with disabilities to achieve productivity, independence and success according to their individual needs and interests.

ATA centers serve people of all ages with disabilities of all kinds and have comprehensive, multifaceted programs that reflect their specific community needs, as well as local talents and resources. For more information about the ATA and the center nearest you, call (800) 992-8111 or (510) 528-0747.

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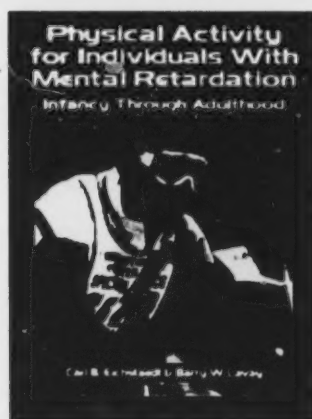
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The following excerpt from Chapter 6: Mainstreaming: Program Considerations has been reprinted with permission from the publisher.

Mainstream Classes

It cannot be assumed that everyone in the mainstream setting will automatically accept and, more importantly, socially interact with the person to be mainstreamed. It is one thing to place a child with Down syndrome into a community recreation program, and quite another for this child to be accepted and chosen for play by the other children in the group. Mizen and Linton (1983) offer the following excellent strategies for preparing the nondisabled group or class for the arrival of the mainstreamed person.

1. Do not ignore individual differences; rather, these differences should be respected. Students should be made to realize that even though each person is unique, there are many

similarities among us. All persons are different and alike.

2. Students should be encouraged to ask questions about various disabilities. For example, a few days before a student with Down syndrome who is to be mainstreamed arrives in class, the teacher can conduct a lesson and discuss with the class why some people have this condition. This would also be an excellent time to conduct a class discussion regarding why people tease one another. With young children, class discussions can include such storybook characters as Tom Thumb.

3. A class session can be conducted in which students can learn and experience "firsthand" various disabilities. One such activity is to partner students, with one partner blindfolded and the other partner

helping her or him negotiate an obstacle course. Another activity is to have students practice throwing and catching a ball with their nondominant hand. After these activities the teacher can conduct a discussion and encourage class members to share their thoughts and experiences.

4. Another strategy that has been effective in a number of districts and recreational programs is to develop a handicap awareness day (Danaher, 1983). For example, a Saturday morning recreational program can be designed in which parents and children (with and without disabilities) participate side by side in various nontraditional games and recreational activities. Persons without disabilities learn about persons with disabilities when they participate with them.

Strategies for Modifying Activities, Games, & Sport

The following is a general list of activity, game, and/or sport modifications that may assist in providing the mainstreamed student with a more productive and positive experience.

1. Design the environment to fit individual needs
 - a. Lower the net in a volleyball game.
 - b. Reduce the size of the playing field.
 - c. Make boundaries more tangible (e.g., use cones, flags).
2. Modify and adapt equipment
 - a. Use large, brightly colored foam balls.
 - b. Use a batting tee rather than a pitcher.
 - c. Use lighter and larger equipment.
3. Reduce the time limit of play
 - a. Use frequent rest periods.
 - b. Reduce the number of minutes played in a period.
4. Develop feedback and

reinforcement techniques

- a. Insert buzzers or bells on goals to reinforce the concept of scoring.
 - b. Reinforce children who display teamwork and share during play.
5. Specific playing positions require certain skills
 - a. Rotate positions, giving each child an opportunity to learn and practice various skills.
 6. Modify degrees of moving objects and mobility
 - a. Have objects (e.g., balls) move slowly.
 - b. Reduce the size of the playing area.
 - c. Increase the number of children participating on a team.
 7. Insure some form of success
 - a. Avoid elimination games.
 - b. Stress self-competition rather than team competition.

BOOK EXCERPT

continued from page 55

(various sizes); Britax Special Car Seat, Columbia Orthopedic Positioning Seat.

Children who must be transported semi-upright or flat

- **Infants:** Evenflo Dyn-O-Mite (may be used with 2" wide velcro strap for prone positioning); Swinger Home and Car Bed; Cosco Dream Ride (up to 12 lbs. in flat position).

- **Toddlers and older children:** E-Z-ON Modified Vest

Children with spica casts

- **Infants and toddlers:** Spelcast Child Car Seat with large conventional child safety seat with a shallow seat may work.

- **Older children:** E-Z-ON Modified Vest

Low birthweight infants

- **Swinger Home and Car Bed** with special bunting for premature infants; Infant only child safety seats such as Evenflo Dyn-O-Mite, Cosco First Ride, Cosco Dream Ride. Do not use any seat with shield or arm rest which could damage the face and neck or interfere with the child's breathing.

Children with glasses, recent facial surgery, or tracheotomies

These children need a device with a five-point harness, *not* a shield or arm rest which could injure the child.

Organizations on safe transportation

Massachusetts Passenger Safety Program, Department of Public Health, 150 Tremont St., 3rd Floor, Boston, MA 02111, (610) 727-1246, (800) CAR-SAFE (in MA).

Safety Belt Safe, P.O. Box 553, Altadena, CA 91003, (213) 673-2666.

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➤ **Disability Benefits in Brief Newsletter.** This 8 pg., bi-monthly newsletter answers parents' questions about their children's SSI, SSDI, PASS, & other benefits. **Free** sample copies avail. in alternative formats and print. **DBA**, 495 E. Ellefson St., Iola, WI 54945, (715) 445-4755.

➤ **Handicapped In Walt Disney World®** by Peter Smith is for disabled people & friends. Learn about accessible trans., lodging, attractions & more. 302 pgs. **\$10.95** + \$3 s&h. **SouthPark Publ. Group**, 4041 W. Wheatland Rd., Ste. 156-359B, Dallas, TX 75237-9991, (800) 669-5657.

➤ **FREE — The NEW Special Needs Project Book Catalog.** Selection of the best books from all publishers about disabilities. Comprehensive resource for parents, children & prof. **Special Needs Project**, 1482 E. Valley Rd., #A121, Santa Barbara, CA 93108, (800) 333-6867.

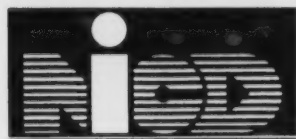
➤ **Prader-Willi Perspectives.** A quarterly journal of medical, educational and other info. about Prader-Willi syndrome for parents & professionals. **\$20** (indiv.), **\$30** (organiz.). **Visible Ink, Inc.**, Disabilities Publ. Group, 40 Holly Lane, Roslyn Heights, NY 11577, (800) 358-0682.

➤ **Free Book Catalog: The 1992 Special Needs Catalog** features a collection of valuable books for children with disabilities and their parents on Down syndrome, CP, autism, spec. ed. and more. Please contact **Woodbine House**, 5615 Fishers Ln., Rockville, MD 20852, (800) 843-7323.

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▼ **Beginning American Sign Language Video Course.** Learn ASL with this fun 16 tape Video Course! Your whole family can learn the Bravo & Billy Seago! **FREE** catalog. **Sign Enhancers**, 1320 Edgewater NW, Ste B-10, Rm. EP2, Salem, OR 97304, (800) 767-4461 V/TTY.



Deafness Center Publishes National Club Directory

The National Information Center on Deafness (NICD) at Gallaudet University announces the availability of their newest publication titled *Clubs of Deaf and Hard of Hearing People*. This directory will be a helpful tool for people who want to locate clubs in their own areas or in areas where they plan to travel or move.

The directory was compiled from the results of questionnaires sent to clubs across the country. In addition to the list of clubs, 12 national associations of deaf and hard of hearing people and their chapters are included.

The directory is available prepaid for \$5 each. Complimentary copies of the 1993 *Directory of National Organizations of and for Deaf and Hard of Hearing People and Publications from the National Information Center on Deafness* will accompany each paid order.

NICD is a centralized source of information on all aspects of hearing loss and deafness. NICD collects, develops and disseminates up-to-date information on deafness, hearing loss, organizations and services for deaf and hard of hearing people.

Send check or money order to the National Information Center on Deafness, Gallaudet University/M93, 800 Florida Ave., NE, Washington, D.C. 20002.

Spinal Cord Injury Information Database Now On-Line

A national database of educational materials on spinal cord injury, sponsored by the American Spinal Injury Association (ASIA), is now on-line. The database, which contains

more than 400 items, helps locate videos, films, booklets and manuals that address the special needs of a person with spinal cord injury, such as coping, recreation and leisure activities, sexuality issues or home modifications.

To request a retrieval, specify the subject area of interest and a printed report will be mailed. Two subject areas will be researched free of charge.

For more information, contact Linda Herson, Division of Education, The Institute for Rehabilitation and Research, 1333 Moursund, Houston, Texas 77030. (713) 797-5945.

Brochure Explains Audiology/Pathology Insurance Coverage

Do Your Health Benefits Cover Audiology and Speech-Language Pathology Services? is a new brochure prepared by the American Speech-Language Hearing Association (ASHA) to help consumers obtain the insurance coverage they need for effective treatment of speech, language and hearing disabilities.

The brochure explains how to file a claim, appeal denial of coverage and ask for better coverage from employers and unions. It also provides examples of services that are covered by some health plans when they are provided by an ASHA-certified speech pathologist or audiologist.

This brochure is available free of charge and can be obtained through the ASHA Helpline, (800) 638-8255.

Service Helps Find Job Candidates with Disabilities

When U.S. employers were asked in a recent survey why they hadn't hired persons with disabilities within the last year, more than half cited a lack of qualified applicants. A new program available to students with disabilities is trying to change that.

The Association on Higher Education and Disability

(AHEAD), a professional organization for persons working in disability service offices on college campuses across the nation, last year launched its National Resume Database for Students with Disabilities. The program offers employers the resumes of some 500 persons with disabilities whose career interests range from aerospace engineering to fine art.

Students with disabilities pay no fee to participate in the database. Employers can obtain the database for \$375 or pay \$175 for a one-time search. So far, about 15 companies and government agencies have bought the database. The Industry Labor Council, a trade organization, has made the database available to some 175 of their members, including AT&T and Ford.

Students who wish to receive a database form should send a self-addressed, stamped envelope to AHEAD, P.O. Box 21192, Columbus, Ohio 43221-0192.



Group Advocates on Behalf of the Dually Diagnosed

The National Association for the Dually Diagnosed (NADD), founded in 1983 as a nonprofit organization, is designed to promote interest, professional development and resources for individuals who have both mental illness and mental retardation.

During the last several years, research has indicated that persons who have mental retardation are highly vulnerable to developing psychiatric disorders.

The division of responsibility between the mental health and mental retardation service systems has all too often resulted in a denial of comprehensive care and treatment for individuals who have mental retardation concurrent with a serious mental health problem.

NADD is a national leading force advocating on behalf of individuals who have mental illness and mental retardation.

The association is committed to a six-fold strategy in serving this population:

- To stimulate public and professional interest.
- To encourage the dissemination and exchange of pertinent information.
- To promote educational and training programs.
- To advocate for appropriate governmental policies.
- To support research focused on identification, diagnosis and treatment.
- To foster the development of resources and services.

Membership is open to professionals, parents, concerned citizens and organizations interested in learning about policy, advocacy, program development and research pertaining to the mental health aspects of mental retardation.

For more information, contact NADD, 110 Prince St., Kingston, N.Y. 12401. (800) 331-5362. (914) 331-4336.

ORGANIZATION NEWS

Conference

• **Niemann Pick Type C Disease Conference**, Just for the Kids of N.P.C., Inc., Mary Boling, 1990 Je-To Lake East Dr., Danville, IN 46122, (317) 745-2738.

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• **Blind Children's Fund**, 8500 W. Capitol Dr., Milwaukee, WI 53222, (414) 464-3000, (414) 464-5693 (fax).

• **Developmental Disabilities Service**, Wagga Community Services Centre, 85-87 Fitzmaurice St., Wagga Wagga, Australia NSW 2650.

New Support Groups

• **Autism Network International (ANI)**, P.O. Box 1545, Lawrence, KS 66044.

• **Trisomy 9 International Parent Support (TIPS)**, Children's Hospital of Michigan, 3901 Beaubien Blvd., Detroit, MI 48201-2196, (313) 745-4513.

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- ☐ Rakow, Sue F. V. & Carol B. Carpenter—**SIGNS OF SHARING: An Elementary Sign Language and Sex Awareness Curriculum.** '93, 380 pp. (8½ x 11), 245 il., \$45.75.
- ☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 x 10), 32 il., 8 tables, \$73.75.
- ☐ France, Kenneth—**BASIC PSYCHOLOGICAL SKILLS FOR FRONT-LINE STAFF OF RESIDENTIAL YOUTH FACILITIES.** '93, 212 pp. (7 x 10), 3 il., \$43.75.
- ☐ Durán, Elva—**VOCATIONAL TRAINING AND EMPLOYMENT OF THE MODERATELY AND SEVERELY HANDICAPPED AND AUTISTIC ADOLESCENT WITH PARTICULAR EMPHASIS TO BILINGUAL SPECIAL EDUCATION.** '92, 182 pp. (7 x 10), 21 il., \$37.75.
- ☐ Silverman, Franklin H.—**LEGAL-ETHICAL CONSIDERATIONS, RESTRICTIONS, AND OBLIGATIONS FOR CLINICIANS WHO TREAT COMMUNICATIVE DISORDERS, 2nd Ed.** '92, 258 pp. (7 x 10), 13 il., \$46.75.
- ☐ Jones, Carroll J.—**CASE STUDIES OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 236 pp. (7 x 10), \$47.75.
- ☐ Schwenn, John O., Anthony F. Rotatori and Robert A. Fox—**UNDERSTANDING STUDENTS WITH HIGH INCIDENCE EXCEPTIONALITIES: Categorical and Noncategorical Perspectives.** '91, 272 pp. (7 x 10), 4 il., 15 tables, \$43.75.
- ☐ Hoffman, Cheryl M.—**SIGN LANGUAGE COMPREHENSIVE REFERENCE MANUAL.** '90, 272 pp. (8½ x 11), \$32.50. spiral (paper)
- ☐ Hughes, Barry K.—**PARENTING A CHILD WITH TRAUMATIC BRAIN INJURY.** '90, 111 pp. (7 x 10), 3 il., \$28.50.
- ☐ Rotatori, Anthony F., Robert A. Fox, David Sexton and James Miller—**COMPREHENSIVE ASSESSMENT IN SPECIAL EDUCATION: Approaches, Procedures and Concerns.** '90, 578 pp. (7 x 10), 22 il., \$97.75.
- ☐ Reavis, Donna—**ASSESSING STUDENTS WITH MULTIPLE DISABILITIES: Practical Guidelines for Practitioners.** '90, 110 pp. (7 x 10), 13 il., \$27.25.
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- ☐ Maloff, Chalda & Susan Macduff Wood—**BUSINESS AND SOCIAL ETIQUETTE WITH DISABLED PEOPLE: A Guide to Getting Along With Persons Who Have Impairments of Mobility, Vision, Hearing, or Speech.** '88, 162 pp. (7 x 10), \$37.00.
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- ☐ Rose, Harriet Wallace—**SOMETHING'S WRONG WITH MY CHILD! A Straightforward Presentation to Help Professionals and Parents to Better Understand Themselves in Dealing With the Emotionally-Charged Subject of Disabled Children.** '87, 210 pp. (7 x 10), \$35.75.
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- ☐ Shearer, William M.—**ILLUSTRATED SPEECH ANATOMY. (3rd Ed.)** '79, 152 pp. (6¾ x 9¾), 91 il., \$31.25.

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"David should have a graduation party, too."

Conflict About Developmental Milestones

"Mel and I are having a big argument about a junior high school graduation party for our son David." Kate Allen, a short, dark-haired woman in her mid-50s, spoke quickly. "David is 15 and is graduating from a junior high school program next week. We had parties for our older son and daughter when they graduated junior high school. David asked us to have a party just like theirs and I agreed. When I told my husband, Mel, we began to have a discussion that we have put off for a long time.

"David was born with cerebral palsy after a long, hard labor. From the start, David has had a lot of difficulty dealing with the everyday problems of growing up that our older children handled so easily. I come from a large family which includes four brothers and sisters and a million cousins, aunts and uncles who all live within 15 miles of where we live now. Mel comes from a much smaller family. Because they live on the coast, we have not seen much of them since David was born.

"Some of what's happened to the way we deal with things came from how much time and

energy we had to devote to caring for David when he was very young. From the beginning, my family has been very helpful. They were available for babysitting, encouragement and, although we never took money from them, we always knew that financial support was available if we needed it. But, I've always felt that Mel has not fully accepted all the help my family has offered us.

"We did change some of our family practices after David was

born. We wanted to include him in everything that took place within our family. But from the beginning, since he was so difficult to handle, we started to cut back on inviting people to even our older children's birthday parties. David's own parties were just celebrated among the five of us.

"Mel has never really shared with me what he has told his brother, sister and parents about David. I think maybe saying he didn't share with me isn't fair, but I'm never sure

how much they know or what they really think. We stopped traveling to visit them the way we did when our first two children were young — some of it because of money and some of it because it's much more difficult as the kids get older. And, of course, taking David would have made things much more complicated. Mel began to argue that inviting family over for the graduation would really involve more time and energy than either one of us have at this point.

"Between dealing with David and the extra costs and paying for our oldest child's college tuition, we're both working day and night. Mel and I have been doing this for a



Illustrations by Robin Courchesne

long time. To a certain extent, sometimes when I've wanted to celebrate, do things or go places with the kids, including David, I've put off trying to discuss Mel's own feelings and thoughts with him. Whenever Mel doesn't want to do something, he always appeals to me by saying that we deserve to rest rather than make extra work for ourselves.

"Sometimes I think that maybe Mel is embarrassed and ashamed of David. Sometimes I feel he blames me for what's happened. These feelings ordinarily come up when we have milestones in David's life that we have celebrated with the other kids and really put off with David. This doesn't mean that Mel hasn't been an exceptionally good parent — he's worked awfully hard and has done more than his fair share of caring for all of them, including our two older kids.

"I want to celebrate this graduation. David may not be a genius and I don't know what he'll be able to do later in life, but he's worked awfully hard and deserves everything he's gotten to this point.

"When I started to say these things to Mel, he began to cry. I was so upset that I began to cry, too. We both thought that if we need to have this discussion, and I think we do, we should have it with somebody who can help us figure out what's going on and what to do."

"Sometimes I'm confused about what I think," Mel Allen, a tall, slender man in his early 60s, spoke quietly. "I do admire David for how hard he works and how much he's been able to do. He's done far more than we ever thought he would when he was born and far more than many of the specialists that he's seen over the years predicted. I know how much my approval means to him. Sometimes it breaks my heart. In the last couple of years he's always saying to me, 'Don't worry, Dad. You'll be proud of me.' Sometimes I say, 'You don't

have to worry, I am proud of you.' But then I'm so uncertain about what he will be able to do when he grows up, if he grows up.

"When the other kids graduated from junior high school, I had a good sense of what they were going to do next — what kinds of lives they were going to lead and what kinds of careers they might have. With David, I'm never sure if he's really mastered whatever it is or where it's going to lead him. I worry about how much we are going to have to do for him for the rest of his



"I want to celebrate this graduation. David's worked awfully hard."

life. I'm never really sure what is a milestone and what isn't.

"I do appreciate the difference between Kate's family and mine. Although both families give me trouble at times, Kate's family has always been available, although sometimes I wish we had more privacy. But I know if we have to count on them, we can. I know they haven't been happy about how restricted things have been around some of the birthdays, and sometimes we don't take David to family celebrations.

"My family is a different story. When I told my brother that David was graduating from junior high school, he asked what he should buy him. When he began to describe the

kinds of things he had in mind, it was clear that he still thinks of David as if he were a very young child. My own sister doesn't want to talk about this at all. She has not been very helpful to my parents and whenever I talk to her, it's almost as if she is wondering what I'm going to ask for and whether she will want to do it. I've talked to my brother about this, and he always says, 'Talk to her, don't talk to me.'

"I have been reluctant to go visit them. The last time I saw them all was five years ago at a family wedding when we didn't take the kids. I think I've listened to words spoken about what David could become when he grows up, but I'm not sure I understand them. I'm not sure that my wife and I have really ever been able to hear or discuss what is going to happen to David later in life. I worry a lot about who is going to care for him. Somehow I never quite feel like celebrating. Sometimes I think David has been a disappointment to me and Kate, but maybe I'm a disappointment to him. I don't know where to start."

Summary and Conclusions

The Allens came in because they had disagreed about having a party for their son, David, who has cerebral palsy. For years, they had limited David's birthday celebrations to themselves and their other two children. Now, David was graduating from junior high school and had asked for the same kind of graduation party that his older siblings had had. Mrs. Allen agreed with him, but she knew that her husband would be unhappy. Mrs. Allen felt that her husband was embarrassed and ashamed of David, although he had always done everything he could to help David.

Mr. Allen argued that he was not embarrassed; he was unsure what graduation would mean to David in terms of the rest of his life. In addition, Mr. Allen was troubled by his

continued on page 64

**WHEN
YOU GIVE
BLOOD
YOU GIVE
ANOTHER
BIRTHDAY,
ANOTHER
DATE,
ANOTHER
DANCE,
ANOTHER
LAUGH,
ANOTHER
HUG,
ANOTHER
CHANCE.**



American Red Cross

PLEASE GIVE BLOOD.



FAMILY LIFE

continued from page 63

wife's family being much more supportive and accepting of David than his own family was. He doubted whether his own family cared as much or was as welcoming.

Every family has its own unique ways of celebrating the important milestones of every member of the family — the adults as well as the children. These milestones are usually part of a family tradition that helps all family members prepare for



"With David, I'm never really sure what is a milestone and what isn't."

the next stage of life and the new challenges to come. The Allens had clearly established a tradition by celebrating the junior high school graduations of their older children. Part of the dilemma of living with and helping a child with a disability grow is that there are no clear guidelines or markers to the kinds of lives they will be able to lead or the kinds of successes they will be able to have. But at the same time, as they grow, their opportunities will continue to expand.

When celebrating important occasion-making milestones, families should start with their own inclinations and wishes rather than any concerns about other people. The Allens had wanted to celebrate. Mr. Allen's

concerns involved including people outside their immediate family. The Allens were able to identify family members as well as close friends who had shared in David's efforts to grow and had really known him during the course of his life. The Allens discovered that these people were happy to share David's achievement with their family.

Milestones and their celebration within a family can cause conflicts, regardless of the abilities or disabilities of a child or family member. They can cause old feelings of rivalry and conflict to resurface, as well as the feelings of shared joy in the accomplishment. Milestones also represent an opportunity for parents to begin to review their own thoughts and feelings about a child and share these feelings with friends and family. When things go well in the life of a child, such a review process is an ongoing one. However, when things are uncertain, as in the Allen family, parents often defer the issue of review and discussion. This means the family has had little opportunity to rehearse the next step in the child's life. Because of this, they are unsure of how to share their feelings, not only with people outside the family, but with other family members as well.

Mr. Allen, with his wife's support, began to see David's graduation as a chance to fully discuss with his own family the concerns and questions he still had about his son. He began to understand something that Mrs. Allen had never shared with him — her concern that he had never fully accepted her own family's willingness and desire to do more. With these incentives, the Allens began to plan for the graduation party, including not only David's ideas but his siblings' ideas as well.

— M.J.S. —

This case has been selected from private practice and consultation files. The names and circumstances have been changed to preserve confidentiality.



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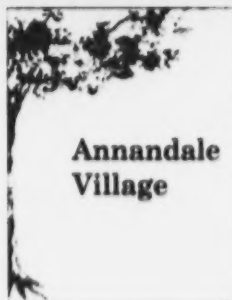


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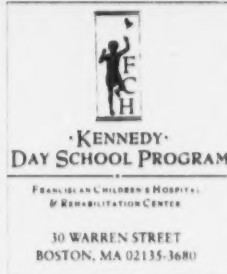
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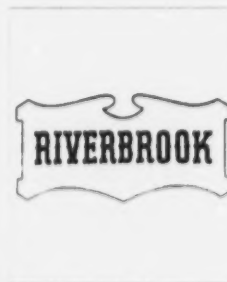
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Young bodies float in a broad expanse of bath-tub-warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex; laughter at splashes and water-antics; shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

The little boy described above does not wear a daytime brace to maintain his range of movement. Instead, once a week, he experiences the intense relaxation of the Hubbard tank. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more coordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young man in the therapeutic pool will also experience a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a movable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the children, when in the pool, to move in ways in which otherwise they cannot: if they cannot walk on land owing to poor strength or joint pain, they might be able to walk independently when in the water, or they might acquire real movement, instead of spasticity. Here, in the pool's supportive warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced - and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multi-faceted program at Berkshire Meadows, a private, non-profit residential school for children and adolescents who are developmentally delayed and multiply disabled. Nestled in the heart of the Berkshire Hills, the attractive and carefully-designed campus also houses several cheerful residences and a Learning Center equipped with state-of-the-art teaching aids. The program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of pre-cognitive, cognitive, pre-vocational and independent living skills. There is an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.



At Berkshire Meadows we believe that all children, no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

For further information, please contact: Ms. Gail Charpentier, Berkshire Meadows,
249 North Plain Road, Housatonic, MA 01236 (413) 528-2523



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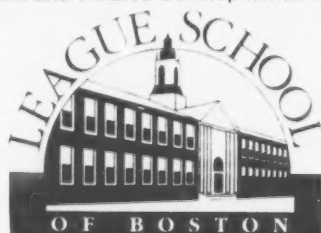
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St. John's Villa

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FAMILY SUPPORT

continued from page 11

But after much research, I have found no replacement diaper for an individual who weighs more than 50 pounds.

I would like to hear from other parents or caregivers who are in the same situation or have similar diapering problems. I would very much like to keep my daughter in this style of diaper. If others feel as strongly, I may create a way to meet the need.

G.M.F.
New Jersey

Dwarfism

Our five-year-old daughter, Kaycie, has an undiagnosed form of dwarfism. She is extremely tiny. She weighs 11 pounds and is 27 inches tall.

She has tiny hands and feet, as well as everything else. Size one shoes are too big, but high tops will stay on. She wears size 12-months with a few adjustments. Her development is somewhat slow. She has had nine surgeries for ear tubes as a result of numerous infections.

If there is anyone out there with a child as small as Kaycie, I would like to correspond with you.

W.A.
Utah

Parents Search is an opportunity for our subscribers to get information from parents about their practical experience in handling the everyday problems of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Anyone who wishes to submit or reply to a letter in *Parents Search* or *Respond* should write to:

Exceptional Parent
1170 Commonwealth Ave., 3rd Floor
Boston, Mass. 02134-4646.

Please indicate whether it is a **search** or **response** letter and in which issue the original letter was printed when addressing a reply. All responses will be forwarded and may be published in our *Parents Respond* column.

For technical information about a disability, we encourage you to contact NORD (P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518) or refer to *The Annual Directory of National Organizations, 1992-93*, in the September 1992 issue of *Exceptional Parent* (available from the above address for \$6 including postage and handling).

When The World Starts Spinning

The people around him started spinning around and around in crazy circles. Jesse struggled desperately to find a familiar face among the swirling images, but everything looked distorted and strange. To Jesse, it felt like the whole world had turned upside-down. In reality, he was lost in a seizure.

For Jesse, seizures were an unavoidable part of living with multiple disorders. At times his reactions were so severe he would inflict bruises on himself. After years of searching for a place where their son could get the help he needed to learn and grow, Jesse's parents found Heartspring.

At Heartspring, seizure management plays an integral part in the individualized programs we develop for each child who experiences seizures. Every member of our staff who works with children is trained in seizure management. We strive to reduce the occurrences of seizures through a balance of diet, physical, occupational and behavioral therapy, and the reduction of medications to a minimum.

13 months after Jesse entered Heartspring, his seizures have been reduced from twice a day to less than once a month. He not only participates freely in class, but plays a tuba, and even enjoys riding a merry-go-round. His parents credit the Institute with the balance their son has found.

For more information on the individualized programs we provide for children who suffer from seizures, call Heartspring.



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1170 Commonwealth Ave.
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Problem: My two-and-a-half-year-old daughter, Leah, could sit independently for only 10 minutes or so. She has cerebral palsy and we've been teaching her to sit for about two years.

For the past eight months I had believed she could sit, but she was always too stiff and nervous to enjoy it, never mind doing another activity at the same time. Her therapists and I discussed giving it up, for a while at least, but I could not do that. If she could sit for 10 minutes, why not for an hour?

As I saw it, the problem was a lack of confidence. Leah didn't believe she could do it. But how do you help a two-year-old believe in herself?

Solution: One day I received a videotape in the mail from my brother which showed his seven-month-old child sitting. What if Leah saw herself on TV, sitting? Could seeing herself doing it change her self-image?

My husband videotaped us sitting on the floor together during one of her 10-minute attempts. That evening we sat on the couch to watch our "movie,"

accompanied by a lot of positive comments like, "Look how well Leah sits" and, "I guess Leah's a real sitter now!"

The next day, Leah sat independently for three hours. I thought I was dreaming. She even played with toys while maintaining the position. There were a few tumbles of course, but she was eager to get back up and keep going.

She's been sitting ever since. I was so proud of her when friends came to visit the next week and Leah was able to sit with them on the floor, at their level, for the first time.

Now I'm trying to think of ways this method could help Leah with her other developmental tasks, including speech.

Cara McCulley
New York

Problem: Recreation is one of the best mediums of self-expression. It gives a child the chance to become a member of a group and the opportunity to belong. Recreation gives all types of children an equal chance, so the child with a physical disability can be reached.

Imagine the frustration of the child who watches the kids on the street playing a pick-up game of baseball. These are children making their own rules, adjusting the game to fit their individual needs and adapting the city street or playground to suit their game. But what about the child with the brace standing on the sidelines? Why shouldn't he be part of the gang? If so many adjustments can be

made, is there not an adjustment in the game for this child?

Solution: In our recreation group, the Philanthropic League of New York, there are children with all kinds of orthopedic disabilities and yet they are active participants in athletic programs. When we play baseball, we adjust the rules to fit the needs of the child. If a child cannot run, he bats; if he cannot bat, he runs; if she is in a wheelchair, she is umpire or scorekeeper. A child is always made to feel that he or she is part of the crowd and belongs.

At times, the adjustment can be somewhat involved. For example, when a child looked up and said to the recreation director, "I love to bat, and now I can, but what happens when I get out in the outfield?" He

was learning to adjust to his disability. Any talk about "working with what you have" would not have satisfied him. The idea of double-decker baseball was born.

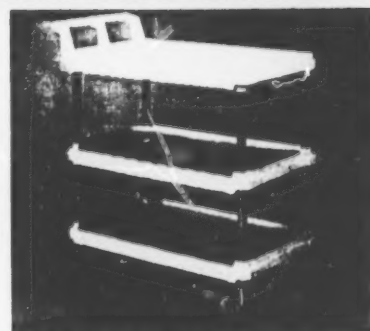
The child grabbed his glove, was placed on the shoulders of the adult, who also put on a glove, and they both played left field. For some reason, the burden on the shoulders of the adult did not seem heavy as she felt the tension, hurt and loneliness leave the little boy who wanted to play outfield, but could not run.

Most active games can be adjusted to meet the physical requirements of these children. It takes a little thought, a little heart and a deep understanding of the trials and tribulations of children with disabilities who want to play.

Susan Samuel
New York

SUPER TIP

Problem: Our 18-year-old son is trying to be independent. However, he has spina bifida and walks with crutches. Carrying heavy or delicate objects is impossible for him.



Cart helps establish independence.

Solution: This heavy-duty plastic cart has rounded edges and is easy to steer. He can put his crutches on the bottom shelf while he uses the top two shelves to set and clear the table, collect laundry, return folded laundry, collect wastebaskets, etc. At school he uses one for his lunch tray and one for his woodworking class to move projects from one workstation to another.

Patricia D. Shanks
Virginia

Handful of Fun!

by Alice Wershing

Slap Happy™ by Cadaco is one of those games that jumps out at you from the shelf in the toy store, saying, "Take me home, there are so many ways you can play with me!" The game comes with four colorful, oversized foam mitts which players fit over their hands and use to slap colored circles on a mat. The die is large and made of foam, making it easy to throw, toss or bounce across a flat surface with just the flip of an arm or kick of a foot. The object of the game is to be the first player to slap the colored circle that corresponds to the color shown on the die. The first player to slap the correct circle earns a point in the form of a cardboard mitt. Up to four players can play this game, and many modifications can be made to allow everyone to play.

The game is designed to be played until one player has collected six mitts. This rule can easily be changed to allow play to continue until all the mitts have been earned. Part of the fun of playing can be designing the rules. For example, players can start the game by dealing out all of the mitts and changing the rules so that the person with the fewest mitts wins. Different rules also allow for the varied abilities of the players. Playing in teams will allow more than four players to actively play the game or assist players who may need help identifying colors. A time period that must elapse after the die is rolled can be used for players who may need longer to locate the correct color with or without the help of a teammate.

The cardboard mitts may be adapted in many ways to make them easier to pick up. Securing them to the mat with double-sided tape or VELCRO™ will allow a player to pick them up when points are earned. Applying magnetic tape, available from local craft stores, to the back of the cardboard mitts and attaching them to a metal surface will provide stability and make them easier to pick up. Another option is to add several layers of cardboard to the back of each mitt to create a larger grasping surface. Players can also devise other methods for keeping score that do not use the mitts at all.

To make slapping the colors easier for some players, hang the mat on a wall instead of laying it flat on a surface. In either case, the position of the colored circles on the mat may be difficult for some players to reach. To

make this easier, cut large circles from construction paper and attach them to material or cardboard to create a new, larger playing area. The number of colors may also be limited. The new playing area may be hung on a wall, laid flat or propped against a surface. Some experimentation will determine the best playing position for all players.

It may be the best fun around, hands down!

Slap Happy™ is available from Kay-Bee Toys or directly from Cadaco, 4300 West 47th Street, Chicago, Ill. 60632, (312) 927-1500.

Alice Wershing is the Computer Resource Specialist and Toy Program Coordinator at the Disabled Children's Computer Group (DCCG): Technology Resources for People with Disabilities, 2547 Eighth Street #12A, Berkeley, Calif. 94710, (510) 841-DCCG.

The author wishes to thank Lisa Wahl and Helen Miller for their contributions to the adaptations described in this article.





Evaluating Feeding Concerns

by Ellen H. King, Ph.D., R.N.

Parents of children with special needs often have difficulty finding the appropriate professional(s) to deal with their concerns about how and what to feed their child. Different professionals can contribute to the understanding of the various aspects of feeding. Only rarely can parents find a multidisciplinary team who understands all aspects of feeding problems and can work with the family to solve the problems.

Parents often find that no one professional can answer all of their questions about feeding. A feeding team, where a variety of professionals work collaboratively with parents to solve feeding problems, is not available in all settings. Parents will want to find professionals who are used to working with children

with special needs similar to those of their child's. Start by asking professionals you now know, including the nearest Parent Information and Training Center, if they can recommend individuals with special expertise. Places to look include children's hospitals, children's rehabilitation centers and university-affiliated programs for the developmentally disabled.

Team Members

An assessment of a child's feeding problems may require the special skills of a number of different professionals with different perspectives. When a multidisciplinary feeding clinic is not available, parents may want to consider creating one from some of the

continued on page 74

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continued from page 72

following kinds of specialists.

Physicians

deal with many issues related to feeding. The physician who knows your child best is the place to start in the evaluation. Most other professionals will want to be sure that your child is free of medical problems

which might cause feeding difficulties or make them worse. The physician will prescribe treatment of the medical problem if one is identified. One such treatment might be feeding by tube rather than by mouth.

Nurses can also evaluate your child's general health via a physical exam with measurement of your child's height and weight. The nurse may want to watch you feed your child so that suggestions about how you interact with your child during meals can be given. Nurses can also help you coordinate the various recommendations you receive from others and provide follow-along. School nurses or other nurses in the community can feed your child or supervise others who feed your child while away from home, particularly if a tube feeding is indicated.

Clinical dietitians or nutritionists evaluate a child's growth and the amount and quality of food eaten. They use weight, height and other measures, including the amount of fat and muscle in the body. Dietitians and nutritionists can provide specific information about the types and amounts of food and liquid your child needs to grow properly. These recommendations should be in terms of your child's special health needs and ability to chew and swallow. Before you go for an appointment, they may ask you to keep a record of what your child eats for three to four days. Be sure to be specific about the amounts your child actually swallows.

Dentists and dental hygienists look at your child's teeth to see if dental health is a factor in your child's eating. They will evaluate the shape of your child's mouth to determine if it makes feeding more difficult. Dentists and dental hygienists give recommendations about how to keep your child's mouth healthy so eating is easier.

Occupational therapists evaluate how your child uses the tongue, teeth and lips and the quality of the swallow. This is important especially if your child is choking. They observe how your child reacts to food textures and different temperatures. Occupational therapists also look at how your child is progressing toward self-feeding and will give you recommendations on how to help your child be more independent in feeding.



Speech and language therapists also look at how your child uses the lips, tongue and teeth. They can suggest changes that will improve both your child's eating and talking.

Physical therapists look at your child's balance and posture as they relate to feeding. They may recommend specific kinds of seating that will make feeding your child easier or help with self-feeding.

Psychologists look at how problem behaviors and a child's environment work together to affect feeding. They may watch your child eat and interview you. Psychologists can suggest ways you can encourage your child to eat better with fewer behaviors which interfere.

Most feeding problems take a while to develop. It is likely that they will take a while to go away. Once parents develop a network of professionals to help, it is worthwhile to keep in touch with them so that you will have an ongoing source of support and information.

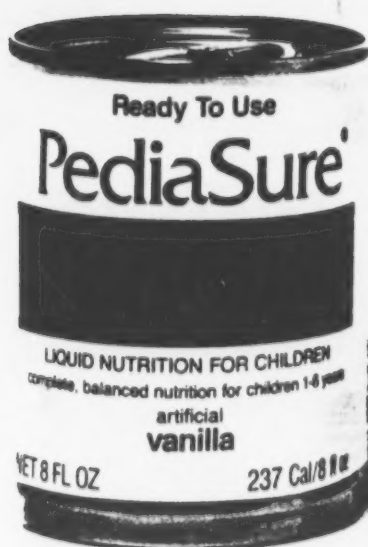
The photos used in this article were taken during an evaluation at the Nisonger Center, Ohio State University, Columbus, Ohio. Our appreciation to the Nisonger Center, as well as Motts Photographic Center, Inc., for providing these photos.



Ellen Hall King, Ph.D., R.N., is Chief of Nursing at the Nisonger Center and Adjunct Assistant Professor in the College of Nursing at Ohio State University in Columbus, Ohio.

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Ryan

by Matt Lutak



Hello, my name is Matt. I am 13 and in the 8th grade. My brother who's name is Ryan is 10 and in the 4th grade. He has Spina bifida. He competes in junior wheelchair sports and does track and field and swimming. He belongs on the N.J. Rolling Raiders for the N.J.W.A.A. (New Jersey Wheelchair Athletic Association). He also did a commercial for Kids 'R' Us. It's sort of fun having Ryan as my brother even though we often fight.

P.S. My brother was the one in the chair in the Kids 'R' Us commercial.

Matt, 13, and Ryan, 10, live with their parents, Roman and Melinda, in Fords, N.J. Matt is an eighth grader at Fords Middle School and Ryan is a fourth grader at Matthew Jago School in Sewaren, N.J. Matt enjoys playing basketball, collecting basketball cards and playing Super Nintendo. Ryan has been involved with the New Jersey Wheelchair Athletic Sports program for four years and collects comic books. Ryan is also on Sesame Street's closing credits every Friday. (He's the one in the wheelchair.)

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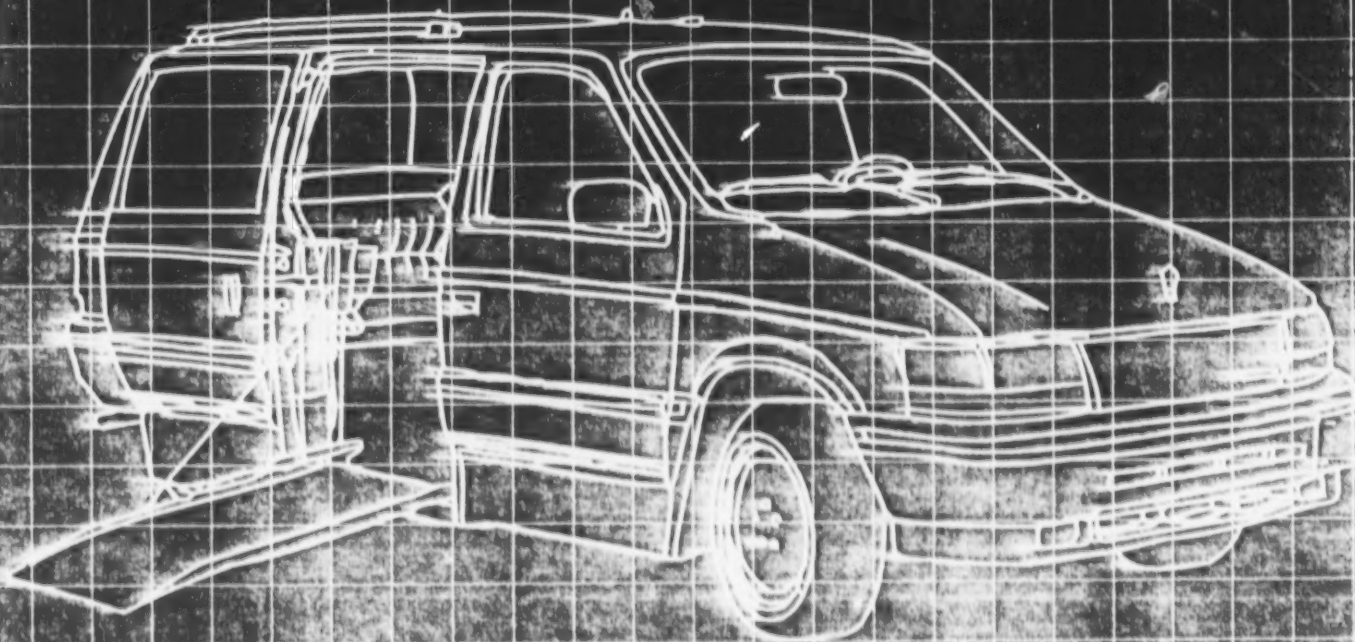
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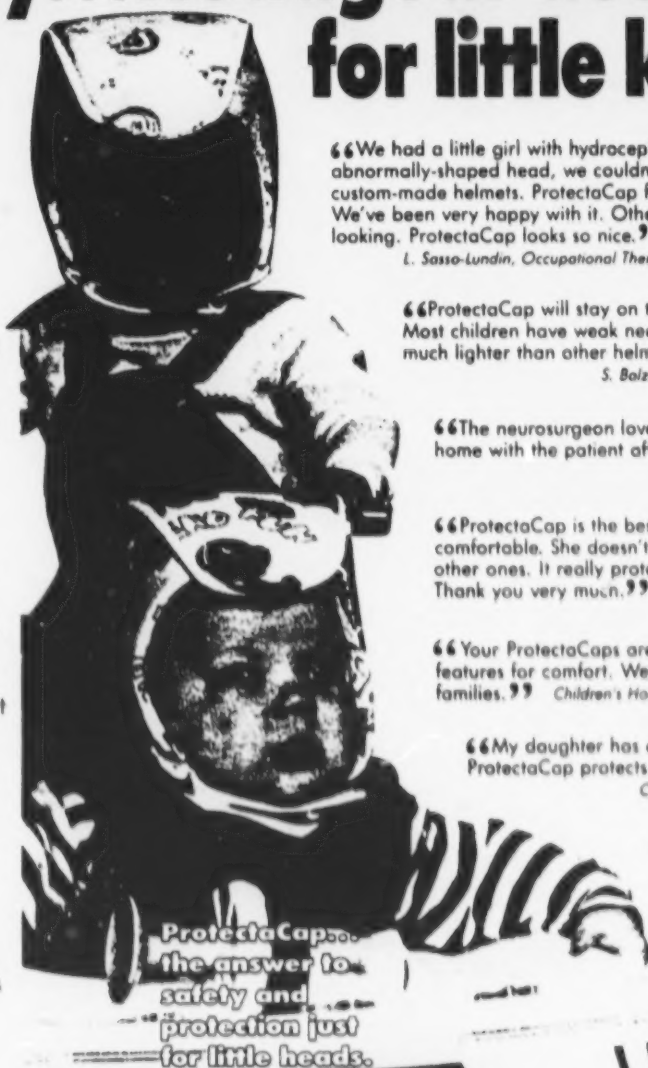
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M. Miller, Parent, Lombard, IL

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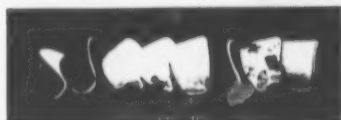
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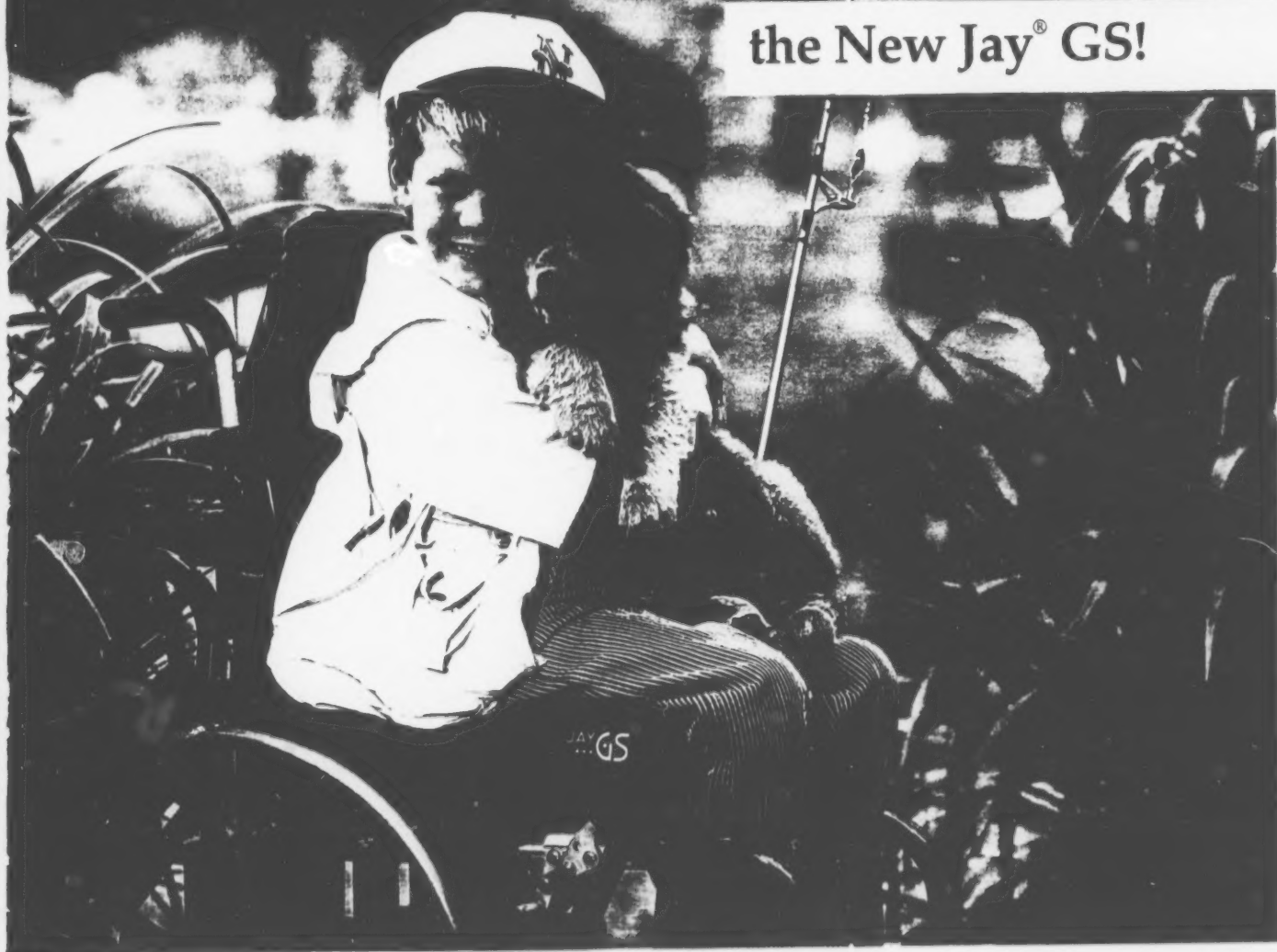
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Exceptional Parent

PARENTING YOUR CHILD WITH A DISABILITY



Cover: Georgia Peaches Ashley, 6, and Jennifer Howard, 8, of Columbus, Ga., smile for the camera. See *Family Album* page 68.

July/August 1993

Volume 23, Number 6

FEATURES

- 16 Learning to See the Bright Side** *by Marianne M. Jennings*
How the joys of raising a child with disabilities can outweigh the challenges.
- 20 Reaching Out** *by Bernice Brooks Bergen*
The importance of support groups for parents of children with disabilities.
- 24 Labels Can Be Harmful** *by Rebecca Viers Padilla*
A mother advocates for the careful use of language by professionals.
- 26 Health Care Reform** *by David J. Dunn*
The president of The Arc describes the principles that can be used to evaluate the Clinton administration's upcoming proposal for health care reform.
- 30 Aquatic Sports**
Many aquatic products are available to make swimming accessible to all children.
- 32 Finding the Fun** *by Jill Baughan, Patricia J. Brown and Monica Uhl*
Setting time aside to play can remind exceptional parents of life's lighter side.
- 36 Family Support Programs Growing**
Most states are offering an increasingly diverse menu of family support services.
- 46 Auto Industry Offers Incentives**
Four major car companies help finance adaptations to make autos accessible.



Page 16



Page 20

DEPARTMENTS

- 6 Family Support** Letters to the Editors, Parents Search, Parents Respond
- 14 Editorial** The Best is Yet to Come
- 50 Technology Bulletin Board** ATA Scrapbook of Success.
- 53 Special Book Excerpt** When Your Child Goes to School After an Injury
- 54 What's Happening** Documentary encourages engineering careers, booklet helps students select a college & more!
- 56 From the Bookshelf** It Isn't Fair!
- 58 Tips for Parents** Mealtime platform, sledding on the beach & more.
- 66 Fun Stuff** *by Alice Wershing* Spills and thrills with *Stretch-Out Sam™*.
- 68 Family Album** *by Jennifer Howard* Ashley Nicole Howard



Page 24

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For more than six months, Max Schleifer and I discussed a new phase in the life of *Exceptional Parent*. This issue marks Max's last as Editor in Chief. After a distinguished career as a clinical psychologist, college professor, author and co-founder of this magazine, Max is now going to be working less and enjoying some well-deserved leisure time and travel. After close, day-to-day collaboration in building *Exceptional Parent* over almost 25 years, the transition process has been a complicated one for both of us.



Stanley D. Klein



Maxwell J. Schleifer

As this process evolved, I began to explore ways to reallocate management responsibilities to ensure that the magazine continues to deliver high quality editorial content while strengthening the way we go about doing our job. Networking with friends and colleagues, I had the good fortune of meeting Joseph M. Valenzano, Jr. in March. For over 20 years, Joe has been a senior executive in the publishing industry as well as a teacher of graduate publishing courses at New York University. He is also an energetic, enthusiastic and caring person and a dedicated parent. Joe has now become the president of the company and has assumed responsibility for making sure that all the elements that result in the delivery of an effective publication work smoothly. Specifically, he will devote himself to circulation development, advertising marketing and magazine production and distribution.

Since neither Joe nor I were interested in relocating, we are pleased to announce *Exceptional Parent's* new office in Hackensack, N.J. (Joe's neighborhood). The editorial office and I will remain in Boston.

These major changes are a source of mixed feelings because they affect real people — and change is always stressful. A number of our dedicated Boston staff will be finding new employment. I am confident that I speak for all our readers when I wish each person the very best for the future and express my personal thanks to each one.

S.D.K.

Judith Heumann to Head OSERS! President Clinton's nomination of California's Judith Heumann to be Assistant Secretary (of Education) for Special Education and Rehabilitative Services was confirmed by the Senate early in July. For more than two decades, Judy Heumann has been an outstanding advocate for people with disabilities, a creative and energetic leader in the independent living movement and an inspiration to many children and adults. Our *21st Annual Education Issue* in September will feature an important article by Judy about her new endeavors in Washington.

Correction. In the June 1993 issue we included an incorrect 800 number for the North American Riding for the Handicapped Association. The correct number is (800) 369-RIDE (7433).

INDEX TO SPECIAL ADVERTISING SECTIONS

SECTION	PAGE #'S	SECTION	PAGE #'S
Product Showcase	41	Marketplace	51, 52
Advertisers Index	41	Media Buyers' Guide	55
Van Conversion Dealers Guide	49	Schools, Camps & Res. Guide	63

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- 1986 - Media Award - The President's Committee on Employment of the Handicapped

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374

Letters to the Editors

Tough Choice Commended

I felt stunned, saddened, relieved and finally accepting after reading *Tough Choice* (April/May 1993).

It is obvious that the Ayres love their son Andy and gave him every opportunity to be successful in an integrated society. Only when every avenue was explored and determined not to be the solution for their son was yet another alternative, a successful one, attempted and secured for him.

Residential care, once the only avenue, is now rarely utilized. Although it is generally not considered politically correct to favor placing a child in residential care, this family illustrates why these facilities exist and why they are needed.

For those of us with young children, it is helpful to know what has worked and not worked for others. Just as we are individuals, so are our children and there is not one "right" way. I commend and thank Carol Ayres for having the courage to publicly share her story.

W.K.
Wisconsin

Film's Description Wrong

I was distressed to see that a description of a film about a child with Down syndrome was headlined "Documentary About Learning Disability..." (*What's Happening*, April/May 1993).

I am not familiar with the film and I do not know the child about whom it was made. It is theoretically possible that the child has learning disabilities, but the far greater likelihood is that a child with Down syndrome has mental retardation. *

We welcome all contributions to *Letters to the Editors*. Please send your questions, ideas and responses to:

Letters to the Editors

Exceptional Parent

1170 Commonwealth Ave., 3rd Fl.
Boston, Mass. 02134-4646.

Learning disabilities and mental retardation are not the same thing! By definition, children with learning disabilities have normal or above average intelligence but because of differences in learning styles and learning needs, they often need special help to achieve their potential. By definition, children with mental retardation have less-than-normal intelligence and need other kinds of help.

To equate learning disabilities with retardation is to do damage to a generation of hard-fought and hard-won initiatives of the Learning Disabilities Association and parent-members like myself. We have worked so hard to have our children's innate intelligence recognized while at the same time building a network of support to enable them to achieve all they can despite some differences.

Please correct your error. Be sure your readers know that you know the difference between learning disabilities and mental retardation.

P.F.
Alabama

Editors' Note: Thank you for an important correction! For more information about learning disabilities, contact the Learning Disabilities Association of America, c/o Jean Peterson, 4156 Library Rd., Pittsburgh, Penn. 15234, (412) 341-1515.

Shared Journey Is Easier

Shortly after my first child was born, I was lucky enough to have somebody introduce me to *Exceptional Parent*. It was a time when I was feeling overwhelmed by everything that encompassed being not only a first-time mother, but also the mother of a child with disabilities.

Initially, it helped just to know that there were many other people who had a child with a disability. The articles and letters gave me hope that the road ahead of me was one of possibilities.

In fact, my first contact with another parent whose child has the same disability as my son was through

Exceptional Parent. We are good friends today and had the opportunity to meet each other when the Make A Wish Foundation flew our families to Disney World in 1991.

Yet, in spite of this sense of connection with others (through the magazine and the support groups to which I belonged), the journey I've traveled has not been an easy one. The recurring grief is there, of course, but there has also been frustration, exhaustion and fear, intertwined with the joy that our son has brought me.

I would like to give other parents a sense of hope and perhaps help some of them realize that it's okay to be less than a "super parent," okay to accept help from others and to understand that raising a child with disabilities is easier when it's a shared journey.

K.M.C.
Minnesota

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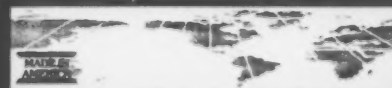
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Parents Search

PDHC and Experimental Medicine?

Our three-year-old daughter, Rachel, has had severe global developmental problems since birth and was recently diagnosed with a rare genetic metabolic disease called pyruvate dehydrogenase complex deficiency (PDHC). She is unable to successfully metabolize carbohydrates into energy.

She is very hypotonic, has a thin corpus callosum and is in the developmental range of about nine months of age. Although many people with this disorder show degenerating symptoms, my daughter is making painfully slow progress.

In researching what information there is on PDHC, I have learned that there are a couple of experimental drugs (Lipoic acid and Coenzyme Q) that have been used to help children with my daughter's disorder. I have

not had much luck obtaining either of these drugs or any information on the risks and possible side effects they may cause. This is mainly because I am having difficulty finding a doctor who is interested in this rare disease and willing to aggressively pursue experimental treatments.

I would love to hear from other parents of children with the same diagnosis, especially those with experience with experimental drugs.

J.K.
California

Angelman Syndrome — Is It Hereditary?

I was originally told that Angelman syndrome was something that happened during my mother's pregnancy with me, and my sister was at no greater risk of having a child with Angelman syndrome than anyone

continued on page 10

F.Y.I.

An Overview of Autism

Autism is a lifelong developmental disability that begins during the first three years of life and occurs in an estimated five of every 10,000 births. It is three times more common in males than in females and has been found throughout the world in families of all racial, ethnic and social backgrounds. Because there are no medical tests for autism, the diagnosis must be based on observations of the behavior of the child. Since symptoms can change with the passage of time, parents of older children with autistic tendencies often must be interviewed about the child's early years in order to avoid misdiagnosis.

The symptoms for a diagnosis of autism include:

- Slow development or lack of physical, social or learning skills.
- Immature speech rhythms, limited understanding of ideas and misuse of words.
- Abnormal responses to sensations like touch, sight, hearing, pain, balance, smell and taste and the way a child holds his body.
- Abnormal ways of relating to people, objects and events.

Many possible causes of autism exist, but these are not definitive. Recent evidence indicates that a physical cause probably affects the development of the parts of the brain which deal with language and the higher organization of information coming in through the senses. No known psychological factors have been shown to cause autism.

Various methods of treatment have been tried, but no single treatment is effective in all cases. However, appropriate programming, based on individual functioning level and need, is of prime importance. There is no known cure.

Highly structured, skill-oriented training, tailored to the individual, has proven most helpful. Social and language skills should be developed as much as possible. Supportive counseling may also be helpful for families with members who have autism. Physicians can usually advise parents as to available counseling services.

In types of autism where metabolic abnormalities can be identified, controlled diet and/or medication can be beneficial. Also, properly monitored medication to decrease specific symptoms can help some autistic individuals live more satisfactory lives.

Resource: Fact Sheet — Autism is published by the Autism Society of America, Inc.

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continued from page 8

else in the general population.

Recently, the story of three sisters who each have a child with Angelman syndrome was published in a medical journal and my doctor said that now they could not safely say that my sister is not at risk.

My sister has not had children yet, but I know she wants to one day. I have three children — two are diagnosed with Angelman syndrome and one is healthy. I would like to hear

from anyone with information about whether or not Angelman syndrome is hereditary.

A.Z.
Maryland

12 p+ Trisomy

My five-year-old grandson, Eric, has a chromosome abnormality known as 12 p+ trisomy. His disorder is closely related to Down syndrome.

Eric has severe mental retardation. He is noncommunicative and

nonverbal. His attention span is extremely poor. Eric is nonambulatory, but he has taught himself to move about quite adeptly by scooting along on the floor, and he has recently begun to take steps with assistance.

I have been told that 12 p+ trisomy is a very rare syndrome, so I would like to find out if there are any parents who have and/or know of other children like Eric. It would be wonderful to start a letter network where we could all learn more about our unique children from each other.

N.F.

North Carolina

Athetoid Cerebral Palsy with Spastic Components

I am the mother of a beautiful four-year-old daughter with cerebral palsy, athetoid with spastic components affecting her left side more than her right and more involved in her upper extremities.

Cognitively, she functions well above her age level and has more determination to accomplish tasks than any child I have ever seen. She does some independent walking with difficulty and has some feeding skills.

I would like to correspond with any parents of a child who is involved in a similar manner. I am also interested in hearing from anyone who has ever used or has some knowledge of biofeedback.

L.M.F.

North Carolina

Addressing PDD and Deafness in School

I am the mother of a six-year-old son who is profoundly deaf. He was born at 28-weeks gestation and spent four months in the NICU. He had necrotizing enterocolitis, a grade four intraventricular hemorrhage, bacterial and fungal infections and spent three weeks on a respirator. He has a left hemiparesis and walked at age two-and-a-half.

He communicates through sign language, although his signing skills are delayed because of fine motor

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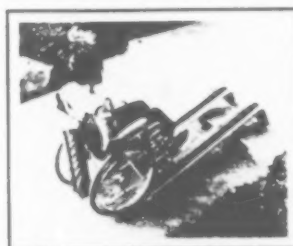
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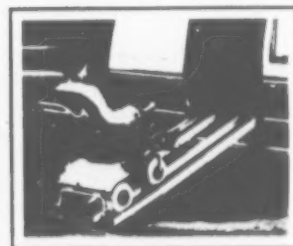


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problems. He is very hyperactive with a short attention span in a group setting. He was recently diagnosed with pervasive developmental delay (PDD).

I am interested in hearing from parents whose children have similar dual diagnoses. His deafness needs to be addressed, preferably in a school for the deaf, but the PDD should be addressed in a very small, structured classroom situation. Any help anyone could give me on how they are handling this situation would be greatly appreciated.

C.R.
New York

De Morsier Syndrome/ Septo-optic Dysplasia

I am the parent of an 11-year-old girl who was diagnosed at six months of age with optic nerve hypoplasia, at nine-and-a-half months with hydrocephalus (shunted) and at two years with agenesis of the corpus callosum.

Earlier this year, I heard a taped presentation on characteristics of children with optic nerve hypoplasia that included a lack of initiative and spontaneity and a tendency to echolalic speech. I felt that a few more of the pieces of the puzzle that make up my wonderful daughter had fallen into place. Determined to learn more, I quizzed her eye specialist and heard De Morsier syndrome mentioned for the first time.

As endocrine problems seem to be part of this syndrome, I then spoke with her endocrinologist who informed me that my daughter did, indeed, have many of the characteristics of this syndrome but that septo-optic dysplasia would be the most relevant diagnosis.

Ironically, I learned that several other local parents have expressed an interest in meeting with parents whose children have been diagnosed with De Morsier syndrome. Our children's hospital is in the process of making these connections but information seems minimal.

Therefore, any information

continued on page 12



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FAMILY SUPPORT

continued from page 11

other parents, as well as professionals, might be able to give us on either of these conditions would be very much appreciated.

S.A.
Alberta, Canada

Ring 10 Chromosome and Feeding Problems

Our 19-month-old son, Graham, has ring 10 chromosome. Our main concern is his poor feeding ability.

Although he has never had to be tube fed, he is still taking only a bottle with formula. He was not able to breast feed. We have had very little success in getting him to eat solid foods.

He is developmentally delayed (physically and mentally), although we don't know how extensive it is. He is very small for his age (about the size of a six-month-old).

He has had successful surgery for bilateral club feet and strabismus in both eyes. He also has single

palmar creases in his hands and undescended testicles.

He rolls back to front and front to back very easily. He sits with some support and is beginning to crawl. He receives physical, occupational and speech therapy.

He is extremely good-natured. He rarely ever cries, but his feeding difficulties continue to frustrate us.

We were told there were only five or six other cases like Graham. We recently received the *Chromosome Deletion Outreach* newsletter (c/o Christine Barr, P.O. Box 164, Holtsville, NY 11742, (516) 736-6754) where I read of three other boys similar to Graham (they had #10 deletions where Graham has a ring #10).

We would love to hear from other parents with a child like Graham.

B.L.B.
Virginia

Seeking Pen Pals

I am an 11-year-old boy with cerebral palsy. I am smart and good looking and I like music and fishing.

I would like a pen pal who is also an 11- or 12-year-old boy. I use a communication board.

A.P.
Massachusetts

Parents Search is an opportunity for our subscribers to get information from parents about their practical experience in handling the everyday problems of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Anyone who wishes to submit or reply to a letter in *Parents Search* or *Respond* should write to:

Exceptional Parent
1170 Commonwealth Ave., 3rd Floor
Boston, Mass. 02134-4646.

Please indicate whether it is a **search** or **response** letter and in which issue the original letter was printed when addressing a reply. All responses will be forwarded and may be published in our *Parents Respond* column.

For technical information about a disability, we encourage you to contact NORD (P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518) or refer to *The Annual Directory of National Organizations, 1992-93*, in the September 1992 issue of *Exceptional Parent* (available from the above address for \$6 including postage and handling).



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Parents Respond

Brain Injury at Birth

From J.L.'s Parents Search, April/May 1993: "My eight-month-old son sustained a brain injury at birth and was given no prognosis or diagnosis. He has a strong little body and tries hard, but I'm just not seeing him do things like I had hoped. I know it's early, but the stress and fear have led me down a path of despair." The following excerpts are from responses to J.L.

People who have faced and continue to face similar challenges often feel as you do. I say feel instead of felt because it is a continual process that improves but has many ups and downs.

Following the discovery that my son Luke experienced extensive, irreversible brain damage, I found the medical community pretty useless. My husband is a physician and I am a nurse, so we found the disappointment very frustrating. We found either an unwillingness or an inability to deal with the problems or dismal, hopeless advice. My advice to you is to find a pediatrician or family physician who admits to not having all the answers but will work with you, be flexible and most importantly, compassionate. We finally did.

I think what has helped the most is defining our own needs, as individuals and as a family, and attending to them. Special needs kids require a lot of physical and emotional work and you have to have some restoring of your own self. Over time, we have found good sitters and amended work schedules to accommodate. We still are limited in our activities, still have a sleep dilemma and I need four hands, but specific times are set aside.

I don't know what your current situation is, but I'm sure you grapple daily with sadness, frustration and some sense of loss. Luke has spastic quadriplegia and profound mental retardation and is blind and non-verbal. But he has an amazing spirit and somehow brings out the best in me. The pain and sadness never

leave, but I have finally felt happy again. I can't say "I wouldn't change a thing," because I sure as hell would. I can say that life goes on.

D.S.
Washington

It is okay to grieve. I grieve over my child and he turned four last week. I think the grieving process

goes on indefinitely and you will learn to recognize it when it encompasses your mood. I hope you will find the "down" days will get fewer and fewer and your "up" days will be the majority.

My son Erik has many diagnoses — so many that I have taken control of Erik's case management and the deal with the physicians is "no new diagnoses or labels!" You probably know by now that doctors

continued on page 44

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The Best is Yet to Come

This is the last issue that I will be organizing as Editor in Chief. Over 25 years ago, when Stan Klein and I began discussions about the best way to communicate with families of children with disabilities, I would never have dreamed of *Exceptional Parent* magazine as it has emerged, the wonderful readership that has developed or the great changes that have taken place to enhance the lives of all individuals with disabilities and their families.

As child clinical psychologists, we had seen how parents had not been invited to actively take part in educational or health-care planning concerning their own children. Instead, they were forced to plead for minimal services because there were very few programs for children with disabilities. Often when parents asked that their children be included they were blamed for expectations that were too high and attitudes that were considered inappropriate, even pathological. Our initial hope was to enable these parents to speak for their own cause — their own children.

In preparing this message, I looked back at our statement of editorial purpose published in the first issue of *Exceptional Parent* in July 1971:

The Exceptional Parent was conceived as a forum for the mutual sharing of the acquired knowledge of both parents and professionals.

... We need to share with each other, to learn from each other and to grow together. Your task and ours are not easy ones. We are dealing with a difficult and delicate problem — the care of children with physical, intellectual, perceptual, and/or emotional disabilities which interfere with their abilities — to get along with others, to learn, and to grow up in a demanding and often unfeeling world. No one expert has the solutions to all of your concerns. The advice of experts in one field may be incompatible with the suggestions of experts in another field or with your family life style.

... *The Exceptional Parent* will provide a wide range of practical information about the human day-to-day problems you face as well as the long-range issues that arise in planning for the future life of your child and your family.

... Our challenge is to provide you with useful information. Our success will depend on your willingness to respond to our material — criticize, praise, and most important, clarify for us what is uppermost in your mind — and on our ability to listen to you. ...



Our readers have been willing to respond and participate. Parents have continually educated us. But most importantly, parents have also found their own voices.

Our dreams in 1971 were limited by our experiences. We have seen changes far beyond those limited dreams. The Education for All Handicapped Children Act began as a dream, then became law with a set of regulations and

is now a part of everyday life in communities throughout the U.S. Today, discussions have shifted to developing strategies for including all children — even those who are considered to have severe disabilities. The recent enactment of the Americans with Disabilities Act has stretched our country's awareness and concerns to encompass the entire life cycle of people with disabilities.

We have seen children and adults with disabilities enjoy expanding opportunities — in education, recreation, employment, marriage, family, etc. We have also seen dramatic changes via the use of technology. What began with very expensive and cumbersome equipment has now expanded to more accessible, affordable equipment available at parent centers and federally funded assistive technology centers around the country — with parents at the forefront. At least as exciting has been the development of the parent movement with ever-expanding parent networks. Parents reaching out to other parents have provided more hope and opportunity than any other single force.

We are proud that we at *Exceptional Parent* have contributed in some way to these changes and will continue to do so in the future. Over the past 25 years, parents of all kinds — rich and poor, young and old — have continually helped shape our ideas and have educated us. In the coming years, as a consulting editor, I hope to be able to do more as I travel around the country, meeting with parents, sharing ideas and continuing the learning that has taken me through these last exciting years.

Looking back, it is amazing to see how far we have come. Looking forward, it is easy to see how much more there is to do. *Exceptional Parent* will continue to play a role in enhancing the energies and the wisdom of parents and professionals working together on behalf of children with disabilities and all children and families.

— Maxwell J. Schleifer, Ph.D. —

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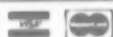
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Learning to See the Bright Side

Drawing from her father's wisdom, the author has discovered how the joys of raising a child with disabilities can outweigh the challenges.

Her daughter Claire has brought her family a new perspective and sense of priorities.

by Marianne M. Jennings

In April 1962 we moved to a new home. Because of school calendar differences, my sisters and I suffered through the pure torture of two extra weeks of classes in our new district. To a 9-year-old child, it was a life sentence. When the first day of our delayed summer vacation arrived, we took to the fields near our home like wild horses. Almost immediately, I was stung by a bee on my right hand. We learned, as my hand swelled to three times its normal size, that I had an allergy. I sat inside for the next four days of June with my now-swollen arm in a sling, miserable from the additional imprisonment fate had handed me.

My father came home after the first day's confinement and talked with me as I gazed out the window at my frolicking friends. His profound words were, "Look at it this way. You won't have to practice the piano for at least two weeks."

In that summer of 1962, my father gave me his greatest gift. It was the first of many times he would remind me of a skill he would label "looking on the bright side," "finding the silver lining in our clouds" and "letting a smile be my umbrella on a rainy day." In exchange I

would give him a roll of the eyes and an "Oh, Dad!" stretched out over a whiny minute.

I didn't know I had my father's gift until our second child, Claire, was born. Claire has what has been generically labeled — in part from exasperation and in part from scientific limits — genetic metabolic disease. The translation? Claire cannot walk, talk, roll or hold up her head. She also has a difficult-to-control seizure disorder.

From friends who learn of Claire or strangers who inquire, the most common response is "Oh, how sad!" or "Such a tragedy!" I don't see Claire in the same way as these folks who missed out on my father's lessons about the bright side of life.

Unexpected Bonuses

I confess that during Claire's first year I went through a time of adjustment, self-doubt and the "Why me?" syndrome. But I have drawn from my father's wisdom and discovered that the joys of raising a child with disabilities can outweigh the challenges. In fact, raising a child with disabilities offers some of life's

greatest moments and sweetest rewards. I begin with the obvious — we get the world's best parking spaces. They are extra wide, thus helping us avoid the "door-ding elves" who occupy all parking lots. Claire brings us valet-quality parking without the requisite tip.

Then there are the airplane trips. We will always pre-board, qualifying under that airline lingo of "passengers needing extra assistance in boarding." In fact, we are always first — even the passengers with small children allow us to go first. The passengers who need assistance assist us. I feel like royalty when we travel with Claire.

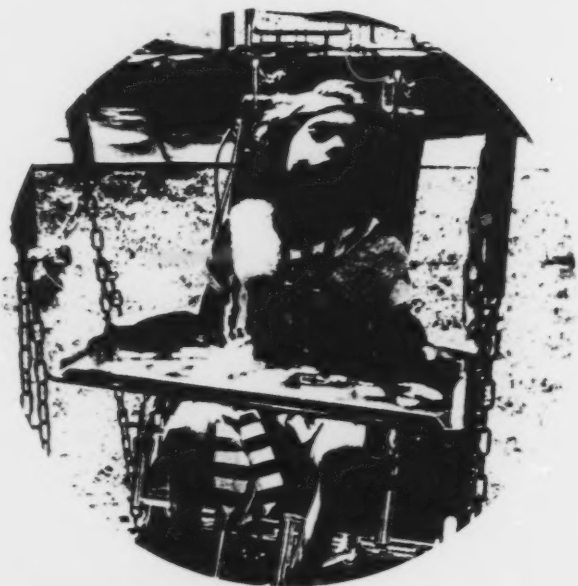
Then there's that door-to-door school bus service. No waiting in the rain. No scrambling to find a seat. No worries for me about the walk between the bus stop and home. It's as close to a limo as we'll come. Royalty again.

We sit in shade and comfort waiting our turn at Disneyland while other families stand in line and struggle in the hot sun. At school, Claire has an individual study plan. It's like a private education without the tuition.

And then there's Claire. She's the only one of my three children who has never argued about what she's wearing. She always looks picture-perfect. There's no back talk, no whining and the only food she's ever turned down is crumbled bacon — a good healthy choice. Sometimes I find myself saying to my other children, "Why can't you be more like Claire?"

Perspective and Priorities

The best part of Claire is that she has brought a perspective and a sense of priorities to me and our family. Claire has taught me to cope graciously with life's challenges. The perspective she has given me allows me to see others' crises as only temporary setbacks. A



Claire enjoys a swing in the sunshine.



Mom and Claire smile for a Christmas card portrait.

mother in our neighborhood spent two sleepless nights and required sedation because her son had earned a "D" on his algebra exam. She is a perfectionist with great plans for all her children and those plans do not include "Ds" in algebra. When I heard of her trials, I looked at our Claire and thought to myself, "A 'D' in algebra? I can fix that. Next ..." A tutor, some extra problems for homework, life moves on. Who wouldn't take a "D" in algebra over life-threatening pneumonia?

I heard of yet another mother who hospitalized her child who had chicken pox so that special precautions could be taken to ensure that there would be no scars from the chicken pox. When I heard of her efforts, Claire's challenges came to mind and I thought, "A chicken pox scar — a little bit of character in a face, a little mark that says 'I was an active child.'" I often listen as mothers speak of a sleepless night because of their children's ear infections. And I think to myself, "One night? I can name the few nights we slept as opposed to all the sleepless ones."

Claire has also taught us to look to the inside of people and ignore the physical issues. I was at a luncheon recently where I overheard a woman saying that she was about to become a great-grandmother for the first time. Someone asked if she knew whether it was a boy or a girl. She responded, "No, and we don't care — just so long as it has 10 fingers and toes." Before Claire, I probably said the same thing. After Claire, I would never issue a physical qualification. I would only say, "No, and I don't care, just so long as they can stay awhile."

Claire has given my other two children a unique sensitivity about others. They befriend those who are

continued on page 18

continued from page 17

ridiculed by others for whatever reason. To them, it is unthinkable to make fun of another's appearance. For me, who did not have a sister like Claire, it was a childhood pastime.

Claire has also given us career and financial priorities. We plan for the possibility that we might not be here and Claire will. We save for those who will care for her and need the financial support she requires. Our focus is no longer on what we achieve but what we can do to make life better for Claire and our other children. Decisions are made based on family needs — not on opportunities or compensation or recognition. Relationships have become our focus because we have had to learn to depend on others for help and support. We need others for advice, information and a pat on the back.

I see the personal growth Claire has brought me. She has given me the lessons life doesn't offer everyone. During a recent rain storm, our roof was

damaged, resulting in a leak in our ceiling. The ceiling was also damaged and needed to be replaced. I spoke calmly with the insurance adjuster and when we were finished with all of our questions and paperwork she said,

"I just have to tell you that you are the nicest, calmest person I've ever dealt with on a claim." I was very proud. My reply came easily, "Hey, we can fix a roof."

Actually, my reply came from Claire. I have learned to fix the things I can fix and move on. For those things I cannot fix from swollen, bee-stung arms to metabolic disease, I've learned to see the bright side. I cannot fix Claire, but I can see the bright side — that bright side is Claire. **HP**



Attorney Marianne M. Jennings is a professor of legal and ethical studies at Arizona State University's College of Business. She is also a columnist for the *Arizona Republic*. Jennings lives in Mesa, Ariz., with her husband, Terry, and three children, Sarah, 10, Claire, 7, and Sam, 2. She received both her undergraduate and law degrees from Brigham Young University. Her article, *The New Shoes*, was published in the July/August 1992 issue of *Exceptional Parent*.

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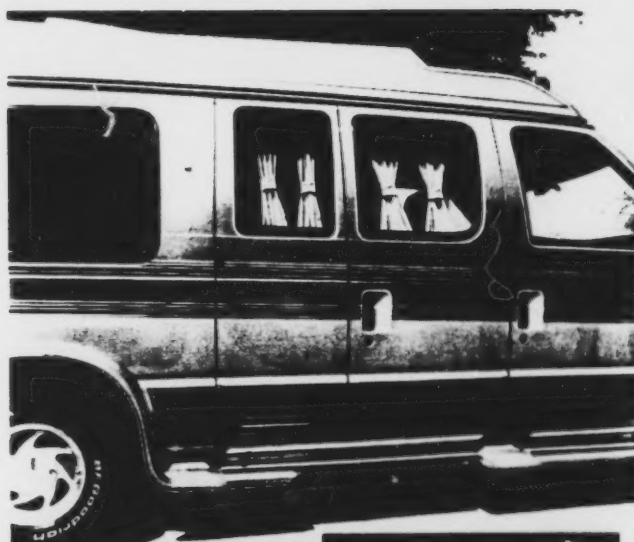
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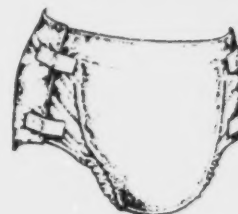
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Reaching Out

by Bernice Brooks Bergen

"Reach out and touch someone" is never more appropriate than when it's applied to those who have disabilities, disfigurements or debilitating diseases. When people meet to ventilate — to share their pain and sorrow — they also exchange wisdom and valuable information. There is great strength in such bonding and a greater impact upon society.

Support Groups

Each decade seems to spawn a particular style of networking. The self-help or peer support group format that emerged in the 80s continues to gain importance and effectiveness. My venture into the network of peer support began because I was born with bilateral cleft of the lip. I wanted to help people with similar problems obtain the right surgery and financial aid.

In 1978, with a small nucleus of dedicated volunteers, I created an ad hoc support group called FACE (Friends For Aid, Correction and Education of craniofacial disorders) to fit our needs. Since then I have become deeply involved with the function of a community-based support group which has grown in numbers and has greatly expanded its free services. The emphasis in these groups is on advocacy, responsible paraprofessionalism from the families and a close relationship with medical and counseling professionals.

Through the years, parents and professionals have

acquired an understanding of each other's roles. It is up to parents to provide other parents with the one-to-one emotional support necessary when dealing with traumatic birth experiences. Understandably, doctors must remain emotionally detached (for the most part). When I founded FACE, I contacted existing support groups nationwide who shared their programs with me. In turn, we

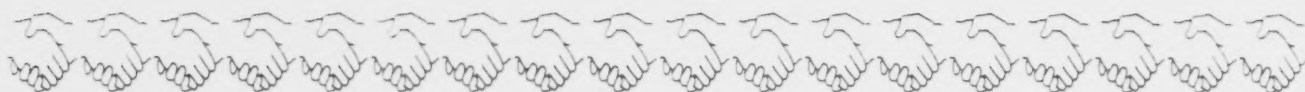
now answer the deluge of requests for information about our own organization. In 1979 there were very few parent groups offering support regarding craniofacial disorders. Today there are more than 200 scattered throughout the United States and Canada. We hope that someday all key cities will provide such resources.

Not everyone has the ability to cope with an existing or ongoing problem. When the problem involves a child who is not "standard issue," coping is often difficult (or sometimes impossible) to achieve without some kind of help. Support groups of all kinds understand the importance of receiving firsthand assurances and of sharing the emotional and deeply personal problems with someone who has "been there."

There is a unique kinship between fellow sufferers that no amount of professional expertise can ever replace.

Most parents of a child with any kind of disability run the gamut of emotions — denial, sadness, anger and guilt — before accepting the reality of a craniofacial disorder or some other disability. For instance, an infant born with a cleft is an awesome sight and the parents,





often in total ignorance of this particular accident of birth, are justifiably frightened. Support groups, if promptly summoned, can guide these troubled people. They can help cushion the shock of giving birth to a child with some kind of disfigurement, paving the way for repair and ongoing treatment (if possible or necessary).

Experienced volunteers can also help parents make decisions regarding the care of a special child that are educated and not based only on emotions, and can help implement a long-range care program. For example, a support group member whose child has successfully gone through corrective surgeries for cleft is able to provide before and after pictures and can discuss the impact of the child's birth on a paraprofessional level.

Such volunteers have become professional in their approach because of long years of active involvement in similar situations. In addition, the special training they have received from the FACE Outreach Program (visitation) qualifies them for an informal type of listening and counseling. They can identify with the doubts and fears, and are aware of all the latest techniques in specific areas.

FACE as an Example

Volunteer support groups are usually parent-led and the services they offer vary from one group to the next. FACE serves as a role model for newly formed memberships. Groups all over the country have adopted its policies, its unique public awareness programs and its staunch policy of advocacy. FACE is one of the few support groups which raises money for educational purposes and to provide financial aid to families in desperate need. All FACE volunteers serve without pay. In 1985, FACE received the prestigious Golden Gavel Award for Service to Youth.

Educational-social meetings allow new and veteran parents to interact in a casual, unstructured atmosphere and have proven their effectiveness. The Sarasota-based group has been cited by the medical profession for its policy of accepting all craniofacial disorders rather than focusing on one anomaly. Since all parents involved share the same fundamental problems, the groups remain close-knit and with the increasing numbers, have more of an impact on the public.

Advocacy

Finally, I believe that advocacy should be the basic thrust of all support groups — the right of any human

Support Group Objectives

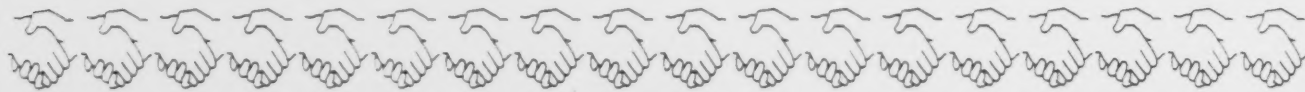
Ideally, support groups in any problem area should offer the following:

- ① Monthly meeting dates to allow ventilation of feelings and sharing of personal experiences, along with educational and information programs.
- ② An educational program structured to promote public awareness of the disorder and any accompanying prejudices.
- ③ The distribution of literature explaining the function of the group.
- ④ A Newborn Outreach Program designed to contact new parents, upon request, as soon as possible after the birth of a child with the support group's disability.
- ⑤ Formation of a resource library containing all available educational materials and lists of service groups and government agencies which offer assistance.
- ⑥ A careful record of case histories handled by the group, including a follow-up of each.
- ⑦ Opportunities for social interaction.

being to receive uniform, quality treatment, and most importantly, the surgeon or treatment center of his choice, regardless of income. Members need to be aware of the obligations of insurance companies to provide adequate coverage for a child who is born with a disorder of any kind and to pay promptly.

Members need to know their rights and that sometimes they must fight for them. On those occasions it is good for parents to know that they can call on fellow support group members to stand by them. Decidedly,

continued on page 22



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continued from page 21



Four FACE children enjoying the sun at a FACE picnic.

there's strength in numbers of people who have the same goal.

The common complaints volunteers hear from troubled people are "Where were you when I needed you?" or "Why didn't anyone tell me about you? I didn't know you existed." There needs to be a vigorous publicity campaign aimed at alerting the community of the existence of local organizations offering guidance and emotional support in specific areas.

You can obtain information about a support group which is appropriate to your needs by calling your local newspaper, social service and health care agencies in your area or a Helpline if one exists in your community. Your doctor or hospital sometimes keeps a list of such services on file.

For your state's Parent Training and Information (PTI) Center phone number, contact the National Parent Network on Disabilities, 1600 Prince St., Suite 115, Alexandria, Va. 22314, (703) 684-6763. A state-by-state listing of PTIs is included in *Exceptional Parent's Annual Directory of National Organizations*, which also lists various national support groups and information agencies by specific disorder or disability. EP



Bernice Brooks Bergen is the founder and executive director of FACE of Sarasota, a support group for people with cranio-facial disorders and their families. She lives in Sarasota, Fla., with her husband, John, and has three sons and twin granddaughters. Bergen was born with a bilateral cleft lip and went on to become a professional actress and model. She is a member of both the Florida and

American Cleft Palate/Craniofacial Associations and received the 1991 National Award for Exceptional Leadership and Contribution Toward Enhancing the Lives of Those With Cranio-facial Disorders from the Cleft Palate Foundation.

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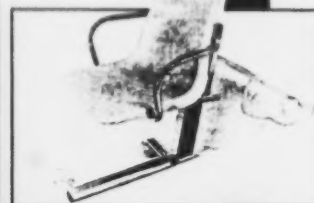
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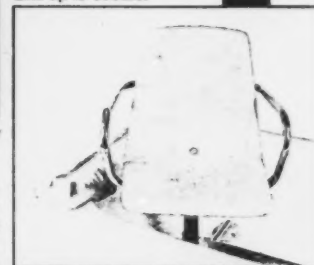


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Labels Can Be Harmful

Advocating for the careful use of language by professionals, the author illustrates how inappropriate "labeling" can lead to inappropriate treatment.

I can still recall vividly the paralyzing disbelief that struck me as the neurologist who gazed upon my baby daughter during her first seizure asked, "How long has she been having fits?" It was 1976. How could a specialized medical professional use such a term to describe my baby? Perhaps he used this language because it was what he had read in antiquated textbooks or what he had heard in his years of medical training.

As I stared down at my baby, her body rigid and jer'ing, her eyes rolled back and her lips turning blue, the words from the uncaring neurologist kept racing through my mind as I searched for a way to interpret them. Did he say "fits"? Hadn't I read this word in some Shakespearean play? Didn't it mean a person possessed by the devil? Images of wild animals with foaming mouths flashed through my mind. Was my baby having a "fit" — an uncontrolled tantrum or a medieval attack? Or was my baby experiencing her first severe seizure? Correct, state-of-the-art terminology describing my child was of critical importance to us at the time.

Likewise, correct, appropriate terminology is equally important today as I listen to professionals describe my

adolescent's neurobiological disorder (NBD) as a "serious emotional disturbance" (SED). The implications of such language are many. SED conjures up an array of images in most of our minds: Aren't these the battered and abused children shown on the 6 o'clock news? Aren't these the children who suffer from poverty, neglect and horrendous parenting? Am I one of those parents? Did I create this disorder?

My daughter was born with an abnormal brain — part of which has been removed through today's modern technology called neurosurgery. The neurosurgeon did not remove anything "emotional" or "behavioral" from her brain. He removed brain tissue, tissue that was malformed and malfunctioning. My daughter's neurobiological disorder has been documented in the UCLA pathology laboratory. The abnormal brain structure has been there since four months gesta-

tion — in utero!

My daughter has always been in a safe, nurturing



Photo courtesy of Jim Thompson/Albuquerque Journal

by Rebecca Viers Padilla

and loving environment. Are her "behavioral" differences the result of what I didn't do right? Or are her differences a *symptom* of a brain that arrived from the birth canal broken and abnormal? How professionals choose to describe her neurobiological disorder makes all the difference in the world to me ... and to her!

Inappropriate labels — Inappropriate Treatment

Let me present but one example of how inappropriate labeling can lead to inappropriate treatment. When my child is hospitalized for her seizure disorder — a symptom of her neurobiological disorder — we are treated like any other family of a child with a medical disorder. Our insurance benefits cover 100 percent of her medical treatment. We stay in the hospital at her bedside 24 hours a day. The hospital staff encourages this level of involvement, offers me a cot next to her bed to sleep on and we are viewed as a caring, involved and dedicated family.

On the other hand, when my child is hospitalized for depression — another symptom of her neurobiological disorder — this same child is admitted to a "psychiatric" facility. We feel fortunate if our insurance benefits cover even 50 percent of her care. In a psychiatric hospital, she is immediately placed in an intimidating and punitive behavior modification program. She begins on "level one" and has limited "privileges," phone calls and family visits (scheduled at the hospital's convenience). If we object to this limited involvement, the hospital staff views us as being "enmeshed" or we are accused of having a "symbiotic relationship" with our daughter. In this "treatment" setting, the professionals are treating what they perceive as her "serious emotional disturbance" — not her true neurobiological disorder.

Professional Sensitivity

The neurologist who described my child's first seizure as a "fit" did not do so because he was a callous,

uncaring man. He did so because that was probably the language he learned in his medical training and because he has never been the parent of a child having a seizure. If he were, he would become instantly and forever sensitized to the importance of selecting appropriate words to describe seizures.

Professionals must give considerable thought to the language they select when speaking to families. Their "patients" are our "children." Our children with neurobiological (or any other) disorders represent our dreams unfulfilled, our hopes destroyed, our futures lost. Their pain is our pain — chronic and unending.

One of my professional partners once used an analogy when we were discussing the issue of labels, terminology and "causation" in relation to children who now fall into the "serious emotional disturbance" category. He

explained that if a tea cup were broken, it really didn't matter whether that tea cup were dropped on the floor accidentally or whether it was thrown against a wall deliberately. What my well-meaning friend fails to realize is that some of the most beautiful "tea cups" in the world simply arrive out of the box broken and forever flawed. EP



Grandma with Jessica at the NAMI banquet last September.

The National Alliance for the Mentally Ill — Children and Adolescent Network (NAMI-CAN) is a national organization offering information, self-help and support group contacts in all 50 states.

For information on children and mental illness, contact NAMI-CAN, 2101 Wilson Blvd., Suite 302, Arlington, Va. 22201, (703) 524-7600.

Rebecca Viers Padilla lives in Albuquerque, N.M., with her husband, Cornelio, and children, Jason, 17, and Jessica, 16. She is the program director for the Pueblo of Laguna Early Childhood Program providing early intervention services to Native American children with disabilities from birth to five-years-old. Padilla is the founder of Parents for Behaviorally Different Children (PBDC), a family-run advocacy organization for residents of New Mexico. To contact PBDC, call (800) 265-PBDC (7232).

*Professionals must give considerable thought to
the language they select when speaking to families.
Their "patients" are our "children."*

Health Care Reform

We Must All Play a Role

by David Dunn, President, The Arc

Last March I was pleased to represent The Arc at a conference sponsored by the Robert Wood Johnson Foundation at George Washington University in Washington, D.C. Hillary Rodham Clinton was unable to chair the conference due to the illness of her father, but she was represented by Tipper Gore. Also present was Donna Shalala, Secretary, Department of Health and Human Services.

I, like The Arc and many of its members, have been following our country's efforts in health care reform. It is sobering to learn that we are spending more than 12 percent of our gross national product on health care and projections are that by the year 2000, these costs could approach 17 to 20 percent. A representative of the auto industry told us that employee health care adds \$1,400 to the cost of producing a car in the United States, compared to \$500 in Japan.

Even though we are making this tremendous financial effort, as many as 37 million Americans have no health insurance. Additionally, one out of five children has not had a polio shot and one out of three has not seen a dentist. We learned that the only countries in the Western Hemisphere having a lower child vaccination rate than the U.S. were Haiti and Bolivia.

So what does all this mean? First, we all should realize that there is a gigantic effort taking place to rebuild and reorganize the nation's total health care delivery system. People are talking about a "seamless system" that reaches out to everyone, and almost daily we read in our newspapers or hear on radio or television about someone discussing "the best way" to achieve it.

One problem is that different terms are used in



Families like Emily, Stephen and Amanda's should not be burdened with disproportionate health care costs.

these discussions and some terms often have different meanings depending on who is speaking. This can be very confusing for many of us.

The Arc has been working with the Consortium for Citizens with Disabilities (CCD) to develop principles we can use to measure the effectiveness of any health care reform proposal. This set of principles gives us a tool to use when we examine the suggestions of different

individuals and groups.

Each of us needs to communicate our support of these principles to our federal and state legislators as they consider the direction of each state and the country as a whole. If we sit back and wait, we may find that the 7 million Americans with mental retardation will not have the health coverage that they need.

With that in mind, I want to cite and underscore these principles. It is useful to keep them in mind as we follow private and public as well as state and federal proposals for health care reform.

Nondiscrimination: All people with mental retardation and other disabilities and their families must be able to fully participate in the nation's health care system. Everyone, regardless of their income, employment, health or disability status must be ensured medically necessary services.

Appropriate: People with disabilities and their families must receive quality and comprehensive health care services including rehabilitation and personal services based on individual need, preference and choice. Also, people must be included in policy making, have a voice in choosing their doctor and have access to effective grievance and due process procedures.

Photo by Charles Joseph, courtesy of The Arc

continued on page 28

Butler

WHEELCHAIR LIFTS STAIRCLIMBS



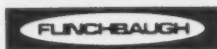
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Comprehensive: The system must provide a comprehensive array of services spanning all service categories and sites of service delivery including, for example, preventive acute care, rehabilitation, long-term services, prescription drugs, durable medical equipment and assistive devices.

Efficiency: This system should be designed to provide services with a minimum of administrative waste and duplication.

Equity: People with disabilities and their families must not continue to be burdened with disproportionate health care costs.

In short, while our nation is working to redesign our health care program, The Arc and our friends and colleagues in the disability community must work together to ensure: that people with mental retardation and their families are included; that the right services are available; that those services can be obtained; that the system is efficient; and that the cost is not an unfair burden.

Nationally, The Arc is playing a major role in efforts to reform our health care system. We continue to participate in meetings with the Clinton Health Reform Task Force to emphasize the disability perspective in acute care, long-term care and personal assistance services. At the same time, The Arc continues an ongoing education

and outreach effort to Congress since the next step will be presentation of the Clinton plan to that body.

This is where we must all play a role. A major change in America's health care system is on the way. All of us must become actively involved to ensure that these changes meet the needs of all people with disabilities. I encourage all of you to let those involved in the redesign of our health care system know about our principles and your support of them. If we wait, we may be too late.

The Arc is the nation's largest volunteer organization dedicated solely to issues of mental retardation. In addition to improving the lives of children and adults with mental retardation and their families, The Arc works to prevent the condition in infants and young children.

Founded in 1950, the organization currently has 140,000 members working through 1,200 chapters in the United States.



David J. Dunn joined The Arc in 1961 after the births of a niece and a nephew with PKU. He currently serves on the Board of Directors and PACTT Committee (technology training for people with developmental disabilities) of his local chapter, Arc of Olmsted County in Rochester, Minn. Dunn has also been a member of other chapters of The Arc in Florida, Connecticut and South Dakota. He has served on many committees and as president and vice president of Arc in Minnesota. Retired from IBM, Dunn is president of D.J. Dunn and Associates, a management and leadership training firm. He is also adjunct assistant professor at St. Mary's University and teaches at the University of St. Thomas and the University of Minnesota.

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It Takes Two To Talk



by Ayala Manolson, M.Sc., CCC

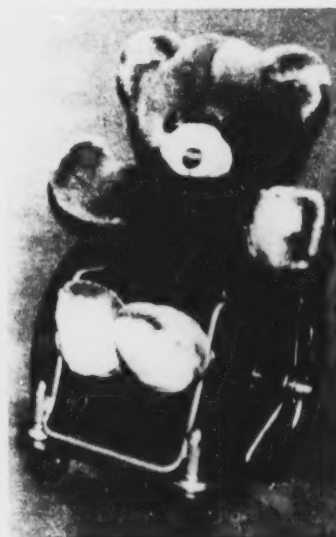
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Sports can provide physical activity and recreation that yield psychological and physical benefits. Potential benefits include improvement of mood-state, reduction of anxiety and depression, increased self-esteem, improved perceived health and long-term reduced risk of many chronic diseases.

The number of people with disabilities who engage in sports and other physical activities has increased dramatically in the past decade, due to the growing field of assistive sports equipment. There are national and international sports associations, and organized competitions for persons with disabilities are now commonplace for many different sports. Whether for competition or simply recreation, the sports equipment market is overflowing with devices to get fans off the sidelines and into the sports arena.

Sports equipment of any kind is designed with the user's safety in mind, but it must be fitted and employed properly. Questions about the type or model of equipment that will be fun and safe should be directed to the product manufacturers, the appropriate sports organization (see the *Directory of National Recreation Organizations*, June 1993), a prosthetist or therapist.

Swimming and other water activities are used in rehabilitation and physical therapy to promote good

muscle tone, lung capacity, flexibility and overall fitness without causing undue pressure on joints or bones.

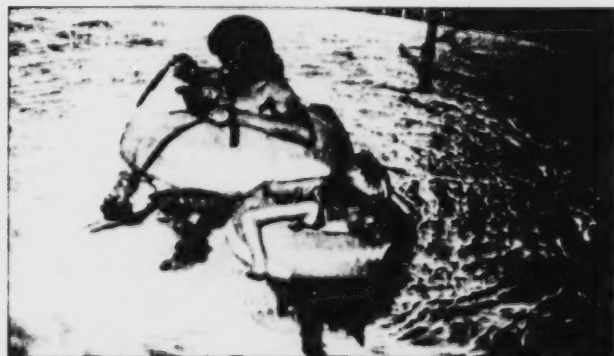
Aquatic activity can be fun and relaxing, and learning to float or swim can lead to participation in other aquatic sports. For advanced swimmers, there are local, national and international competitions.

Flotation devices are designed to keep either a person's entire body or specific parts of the body afloat. Most flotation aids are made of vinyl-coated soft flotation foam with adjustable straps to attach around arms, legs, the torso, the head or the neck. Sizes are based on the user's weight. Flotation devices are good for persons with some head and neck control and to help compensate for uneven weight distribution. In addition to helping a person maintain a horizontal floating position, some models will maintain vertical positions in the water for walking/gait exercises and for games such as water polo.

Swimming aids take a variety of forms, including rings, harnesses, platforms, belts and bars. Platforms generally allow free movement of the head, arms and legs while providing buoyancy to the swimmer. Harnesses may or may not have head and neck supports and are designed to maintain the body in a usual swim position. Flotation bars consist of flotation rings or balls at either end of a plastic bar which the swimmer can grab for kicking exercises or place under the thighs or arms for resting positions.

A pool lift transfers people with mobility disabilities into a swimming pool. Models vary according to the hoisting and lowering mechanism (hydraulic, drive or geared lifting mechanisms), whether they are portable or permanent models, whether the lift is self- or attendant-operated and whether the model is geared toward institutional or residential use. Different models are designed for deck-level pools, above-ground pools or both. Maximum weight capacities vary from 250 to 400 pounds. Transfer seats may be sling or chair types and most have belt or safety strap options. Some models are available with head, chest or adjustable leg supports.

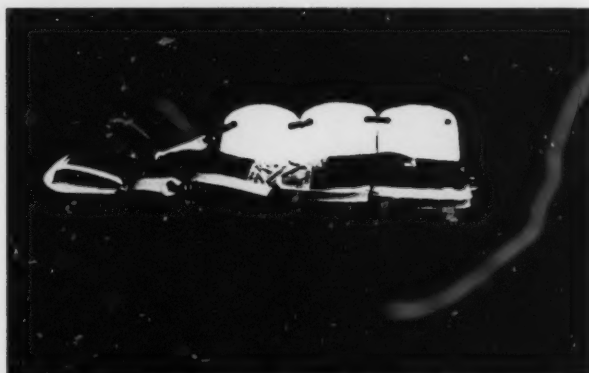
Other pool access equipment includes portable or



The Water Walker from Aquatic Therapy improves muscle tone, coordination and postural control.

permanent stainless steel ramps with handrails for aided ambulatory or amphibious wheelchair entry into the water and pool steps descending from a transfer bench or chair for wheelchair users with sufficient upper body strength to ease down each stair.

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The Sectional Raft from Danmar is for people who are not going "swimming" and are insecure in the water.

This article has been adapted from ABLEDATA Fact Sheet, number 15, December 1992, entitled Aquatic Sports and Recreation Equipment. ABLEDATA is located at the National Rehabilitation Information Center (NARIC). NARIC is a library and information center of disability and rehabilitation. NARIC collects and disseminates the results of federally funded research projects and manages the REHABDATA bibliographic database which contains citations and descriptions of the material in the collection.

For copies of the fact sheet (single copies are free) or more information, contact ABLEDATA, 8455 Colesville Rd., Suite 935, Silver Spring, Md. 20910-3319, (800) 227-0216 or (301) 588-9284 or call ABLE INFORM, an electronic BBS, at (301) 589-3563 with the modem settings 2400 baud, 8-N-1. Both ABLEDATA and NARIC are funded by the National Institute on Disability and Rehabilitation Research (NIDRR), with contracts numbers HN92026001 and HN90028001, respectively. Both are operated by Macro International, Inc.



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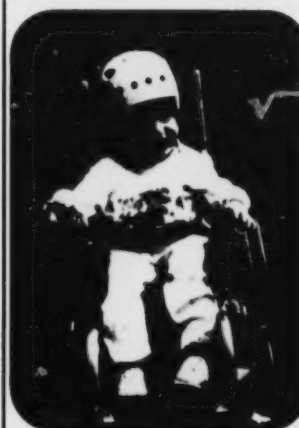
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Finding the Fun

The Importance of Play for Parents

"People tell me I'm handling all this so well," said Meg. "They have no idea that I just put on my 'happy face' when I leave the house. To be perfectly honest, there are days when caring for David so overwhelms me that I don't even want to get out of bed. I just want to take a vacation back to the days when I had no worries, no cares — nobody to think about but myself."

Who among us hasn't longed for that total abandonment of time and responsibility, even if it's only for a little while? How often do we as adults take time to do ourselves a favor and really play? Remember catching fireflies on a summer night? Going to birthday parties and playing *Pin-the-Tail-on-the-Donkey*? Running through the sprinkler in the yard? Sitting in a restaurant and trying to hang a spoon off the end of your nose?

Unfortunately, these are only memories for most adults. Many of us have lost — or at least neglected — the art of playing, and it's no wonder. Parents of children with disabilities have an endless list of "things to do"; not only must we care for the child with a disability, but also for other children. Not only must we make a living, but also maintain a household and all the relationships within that household. Too many things need doing, and we don't have a minute to waste.

Guilt also keeps some folks from playing — guilt

that may come from leaving a child with a disability in someone else's care. But Susan, mother of 7-year-old Wayne and three younger children, says, "I hire a sitter one day a week. I may not be gone for the whole time, but I may run, shop, meet a friend for lunch. And the time I spend away 'playing' makes me a better mother when I come back."

Certainly this time away is important — even vital — to maintain a sense of self. But there's still another reason to develop a daily habit of play — with or without

your child. Your life may have been pretty ordinary a few years ago. Then your child was born, something was wrong and all your idyllic dreams of parenthood evaporated as reality hurricaned in:

- Endless appointments with doctors and teams of professionals ("Will this ever end? I'm the parent. Why do I feel like the one with the least control here?")

- The medications.

("Am I giving him the right amount? Is she getting this at the right time? What if he has a negative reaction to it?")

- Educational planning. ("I never heard of an individualized education plan before; now all I hear is IEP.")

- Talk of respite. ("I really do need a break from all of this but how? When?")

- The countless details that can pull the most positive person into a negative hole.



Dewey Brown shows his son Patrick the finer points of fishing.

by Jill Baughan, Patricia J. Brown and Monica Uhl

Over time, life can become so very serious. You need to be reminded that there's a lighter side somewhere — and learning how to play again can help you find it. Here's how:

Let Go of Time

Ironically, you might have to plan to let go, but so be it. Don't be afraid to block off a period and intentionally forget your watch. Or, decide to play until you're really ready to quit. This can work especially well if you choose to play as a family. Susan makes sure to buy a couple of active board games with simple rules (such as *Hungry Hungry Hippos*TM) that the whole family, including Wayne, can enjoy. Then her family spends one evening a week playing for as long as the children want.

Similarly, if your child wants to play in the mud or dance around the house, join in — not for “just five minutes,” but until you really feel like stopping. Take a moment to watch little ones sometime. Watch how absorbed they become in their own play, and you'll find that it really is possible to suspend time, even if it's just temporarily.

Be Spontaneous

So maybe it *has* been a while since you dusted under the bed. Or, your schedule may dictate that you've got to clean the house. Society may pronounce you “too old for that stuff” when you entertain a desire to turn cartwheels in the yard. But spontaneity, another prerequisite of play, has its own reward — liberation.

Try to respond to the voice that's telling you what you really want to do, with or without your child. Blow bubbles, fly a kite, go to the library and drink in the silence, buy a water pistol and use it, try juggling or a few tricks with a yo-yo. Invite some friends over for a no-stress party (even planned play can include some spontaneity). Let them dress down, bring food and play fun and physical games such as *Hide and Seek* or *Name That*

Time. You can have a basic plan for an evening and still be open to a lot of surprises.

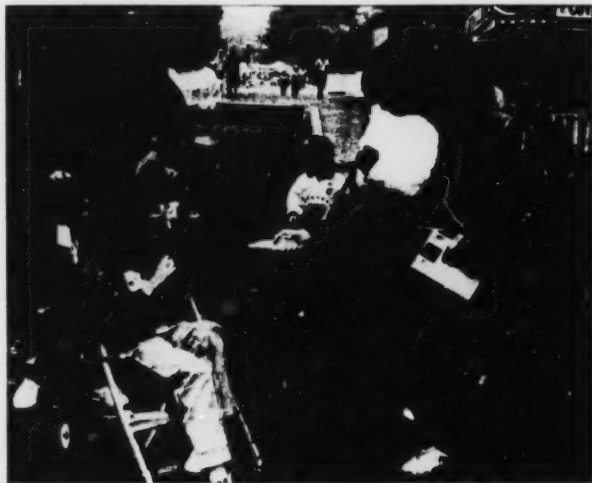
Maintain a Sense of Humor

This should make it easier to keep your sense of humor — a third precursor to play. If you've forgotten or you're out of practice, it's necessary to relearn how to be silly. And if you're afraid of looking foolish when you're acting silly, consider this: much of play's therapeutic value comes from a childlike vulnerability that delights in the absurd. In other words, who cares if you look goofy, as long as you're having fun.

So go ahead — dress up like a leprechaun on St. Patrick's Day or like Cupid for Valentine's Day. Send yourself to somebody — sing on their answering machine. Line three people up in front of a big mirror and tell everyone to make a ridiculous face on the count of three. Walk in the rain with your bathing suit on (fun for singles, married people, families and entire neighborhoods.) Once you get the hang of being silly, it may become second nature to you and, at least for a while, you can take yourself more lightly.

Take Some Risks

Finally, playing might well involve trying something new, so don't be afraid to take some risks. Be a participant, not a spectator. Helen, for example, has a son who is old enough to be eligible for the youth group at church. However, he is far behind the other teenagers in emotional and intellectual maturity. Searching for a way to help with the group and at the same time find a place for her son Chad, she enrolled in and graduated from clown college and led the clown ministry, which included Chad. Is there anything you've wanted to do but never felt you had the time to pursue? Canoeing? Rock climbing? Backpacking? Writing? Maybe you'd want to take a class or, if that's too much of a commitment, a workshop in an activity that would be pure pleasure for you. And

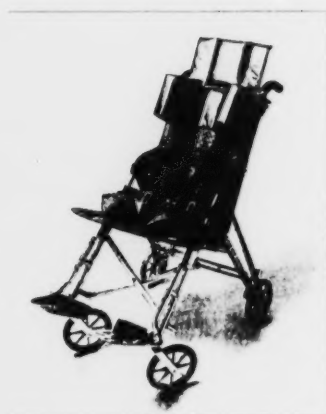


How to Find the Fun

- 1. Let go of time**
Even if you have to plan to do so.
- 2. Be spontaneous**
Even if you feel silly or goofy, it will be liberating.
- 3. Maintain a sense of humor.**
Take yourself more lightly. You'll feel better.
- 4. Take some risks.**
You don't have to be good at something to have fun doing it.
- 5. Keep a positive attitude**
It won't make life trouble-free, but it will make life more joyful.

continued on page 34

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continued from page 33

remember, you don't have to be good at something to have fun doing it.

Keep a Positive Attitude

One final requirement for a playful mind-set — an upbeat attitude. Granted, this is easier said than done. But try this: at the end of each day, in a special notebook designated for just this purpose, take five minutes to write down a few of the day's pleasures. Sometimes this takes some serious digging, but even



Parents can learn how to have fun by watching their children play.

the worst days have their redeeming moments: a soak in the tub, extra cheese on your pizza, an "I love you" in word or deed from someone you care about. Especially during low times, there's something very healing about

filling an entire book with the rightness of life. Then make a list of ways you'd enjoy playing (by yourself, with your spouse and with your family), post it somewhere visible and make sure to play a little every day. It's true that hanging a spoon off the end of your nose won't make life trouble-free, but finding the fun stuff in life might give you a lift, shorten your day and make this business of living just a little more joyful. **EP**

Jill Baughan, Patricia J. Brown and Monica Uhl are all affiliated with Virginia Commonwealth University. Baughan is an English instructor at VCU and a freelance writer. She lives in Mechanicsville, Va., with her husband, Ben, and daughter, Jamie, 12, and is "committed to helping people avoid taking themselves too seriously."



Jill Baughan



Patricia J. Brown

Brown is the Director of Continuing Education and Community Programs at VCU and is Project Director of The Respite Resource Project at VCU's Virginia Institute on Developmental Disabilities. She lives in Richmond, Va., with her husband, Dewey, and sons Christopher, 8, and Patrick, 16, who has Cri Du Chat syndrome.

Uhl is the Project Coordinator for The Respite Resource Project at VCU's Virginia Institute on Developmental Disabilities. She lives in Richmond, Va., with her husband, John Oat. Uhl has worked with various disability organizations because her sister has severe developmental disabilities.



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Family Support Programs Growing

More states offer an increasingly diverse menu of family support services than ever before

Imagine a long hectic weekend spent caring for your children, including one child with a physical disability. You turn your back for one moment and a child throws his toy across the room, shattering the front picture window. You can't afford to replace the window, but you cannot live with a hole in your window, either.

What can you do? Where can you turn for help? Family support programs, which once offered only respite care, now provide a wide variety of services and financial assistance to help parents of children with developmental disabilities or severe emotional problems to deal with the ordinary and not-so-ordinary challenges of daily living. A cash subsidy for window repair could resolve the unexpected crisis.

Current Status of Family Support

More states offer an increasingly diverse menu of family support services than ever before. Forty-eight states offer some form of family support. Some have more than one department or agency that provides family support — usually under the auspices of services for people with developmental disabilities or mental retardation. Of the 70 programs available, almost half are protected by state laws — so they are less likely to be

FAMILY SUPPORT IS...	
CORE SERVICES	OTHER NEEDS (CONT.)
RESPIRE AND CHILD CARE	<i>Home Repairs</i>
<i>Respite</i>	<i>Utilities</i>
<i>Child Care</i>	TRADITIONAL DEVELOPMENTAL SERVICES
<i>Sitter Service</i>	Evaluation/Assessment
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<i>Home Modification</i>	Skill Training
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SUPPORT	Allowances
<i>Family Counseling</i>	Vouchers
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OTHER NEEDS	
<i>Special Diet</i>	
<i>Special Clothing</i>	
<i>Health Insurance</i>	
<i>Transportation</i>	
<i>Vehicle Modification</i>	
<i>Rent Assistance</i>	

Source: *Family Support Services in the United States: An End of Decade Status Report*, February 1990, page 40, Human Services Research Institute (HSRI), 2336 Massachusetts Ave., Cambridge, MA 02140

cut from the budget. Programs may pay for or provide respite care, home nursing, physical therapy, counseling, home adaptations or case management, as well as other services.

In spite of improved family support programs, it is almost impossible to anticipate the unique needs of every family. So more and more programs offer a combination of services and cash assistance. Cash subsidy programs pay for services or products — such as washers and dryers for families with children who have incontinence problems — that are not covered by insurance or other sources of financial aid.

continued on page 38

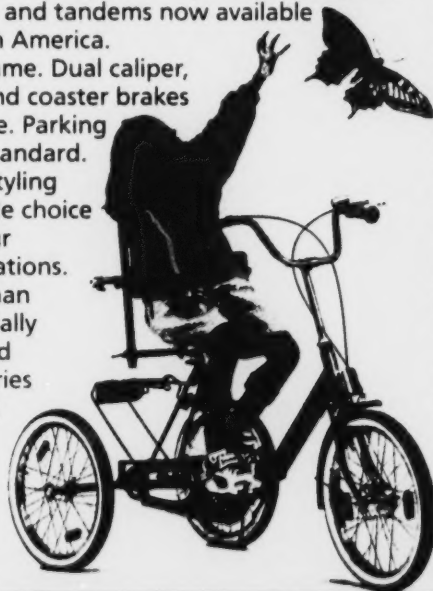
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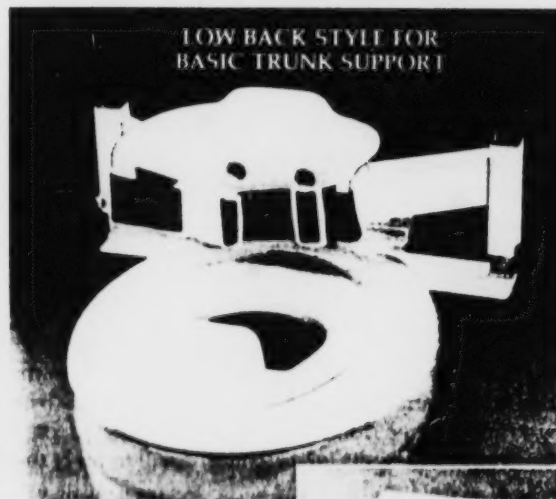
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But family support services, let alone cash subsidies, are not automatically available. The menu of program services differs from state to state. Eligibility requirements also vary. Some programs offer full services to a few families chosen by lottery. Others provide assistance such as cash subsidies to many families but place

The challenge for state governments is to make sure that evolving systems of family support respond to the needs of all families — regardless of race, creed, economic status or ability/disability level.

tight restrictions on what they will cover. Even in many states where family support services are required by state law, families often don't get the help that they need.

Support budgets are often too small to meet the needs of every family. Some states spend as little as \$20,000 each year and support only 15 families. Others spend as much as \$50,000,000 on 60,000 families. In fact, nationwide only about three percent of developmental disability funding is spent on family support programs; however, that's better than three years ago, when family support received only one-and-a-half percent.

Trends

Family support is gaining momentum. More and more advocacy groups for parents of children with special needs are rallying for better services for families. Along with state officials, they are taking steps to create family support legislation.

In 1990, 19 states had 20 mandated programs. Today more than 25 states mandate an estimated 32 programs and several other states are considering legislation. Organizations such as the Family Support Syndicate work together to influence new legislation.

Support services are more available than ever and cover an increasing range of needs. Family support used to be synonymous with respite care. Today the range of available services is limited only by budget and imagination. Programs attempt to be flexible and varied enough to meet the unique needs of each exceptional family. In 1990, 14 states offered combined programs — cash subsidies with direct services; 19 states offered combined programs by 1992. The number of programs is growing (see table, page 40).

State-by-state eligibility criteria for family support services, which used to target only families of children

with developmental disabilities, are beginning to include families of children with chronic illnesses or severe emotional disorders. Some experts suggest that families of all children with disabilities be considered together rather than in separate family support programs based on specific disabilities.

Values that grew out of the family support movement — such as the right of children with disabilities to be educated in regular public schools with other children — are beginning to find their way into human service programs available to all families. Families and service providers are beginning to look for ways to use ordinary, readily-available resources to support children with disabilities and their families. For example, the St. Louis branch of the Young Men's Christian Association (YMCA), the largest day-care provider in the United States, worked with local family support groups to include children with disabilities in day-care programs.

Goals for the Future

In spite of great strides over the last few years, family support still has a long way to go.

- Family support services can help steer people through the system by identifying resources, offering expert advice and advocating for the rights of families in an efficient, caring manner. Currently, some state programs are criticized for not using their relatively scarce funds efficiently.

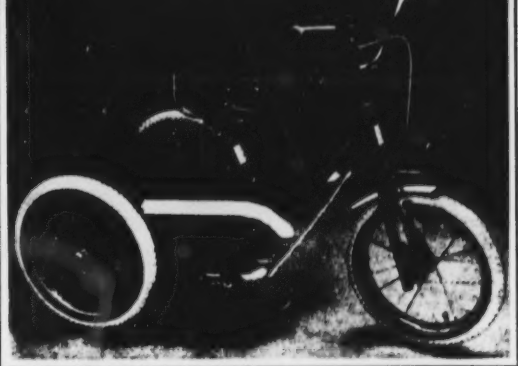
continued on page 42

FAMILY SUPPORT PRINCIPLES

- Families are the greatest natural resources for children.
- Children need enduring everyday relationships with families.
- Each family has unique needs. Supports should be tailored to those needs by being flexible, readily available and sensitive to cultural differences.
- Supports must address whole families, not just children with disabilities.
- Each family should be involved in the process of planning, using and evaluating support services.
- Supports should promote family unity.
- All families should be able to choose from a coordinated menu of statewide services.

Adapted from *National Family Support Legislation to Become a Reality in 1993*, United Cerebral Palsy Association. Copies available from UCPA, Allan Bergman, 1522 K Street, NW, Washington, D.C. 20005.

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Alaska	S	No	(907) 563-5355	New York	B	Yes	(518) 432-8233
Arizona	B	Yes	(602) 542-4049	North Carolina	B	No	(919) 733-6566
Arkansas	B	No	(501) 661-2589	North Dakota	B	Yes	(701) 224-3219
California	S	Yes	(916) 322-8481	Ohio	B	Yes	(614) 466-5205
Colorado	B	Yes	(303) 894-2348	Oklahoma	F	No	(405) 521-4977
Connecticut	B	Yes	(203) 725-3829	Oregon	B	Yes	(503) 373-7555
Delaware	S	No	(302) 739-3333	Pennsylvania	B	No	(717) 787-6057
District of Columbia	B	Yes	(202) 724-5466	Rhode Island	S	Yes	(401) 464-3191
Florida	S	Yes	(904) 488-4180	South Carolina	B	No	(803) 734-0465
Georgia	S	No	(404) 657-2126	South Dakota	?	No	(605) 773-6415
Hawaii	B	No	(808) 586-8100	Tennessee	B	Yes	(615) 741-3805
Idaho	B	Yes	(208) 334-2178 (800) 544-2433*	Texas ⁴	B	Yes	(512) 323-3254
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Indiana ²	S	Yes	(317) 232-7770 (317) 232-7773	Vermont	B	No	(802) 241-2612
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Kansas	B	No	(913) 296-2608 (913) 296-2609	Washington	S	Yes	(206) 753-3900
Kentucky	B	Yes	(502) 564-7842	West Virginia	S	Yes	(304) 558-0416 (304) 558-2376 (TDD)
Louisiana	B	Yes	(504) 342-6804	Wisconsin	F	Yes	(608) 266-7826
Maine	S	Yes	(207) 289-4213	Wyoming	S	Yes	(307) 777-7230 (800) 442-4333*
Maryland	S	Yes	(410) 333-3688	NATIONAL OFFICE			(202) 347-1234
Massachusetts	S	No	(617) 727-6374	1 = As of October 1, 1993			
Michigan	B	Yes	(517) 334-6123 (517) 334-7240	2 = Governor's Planning Council for People with Disabilities			
Minnesota	B	Yes	(612) 296-4018	3 = Information Center for New Mexicans with Disabilities			
Mississippi	?	No	(601) 359-6238	4 = Texas Mental Health/Mental Retardation Program			
Missouri	B	Yes	(314) 751-8611	5 = Utah Governor's Council for People with Disabilities			
Montana	B	No	(406) 444-1334	6 = Virginia Board for People with Disabilities			
Nebraska	S	Yes	(402) 471-2330				
Nevada	B	No	(702) 687-4400				
New Hampshire	B	Yes	(603) 271-3236				
New Jersey	B	Yes	(609) 292-3745				

Key to Codes

S = services

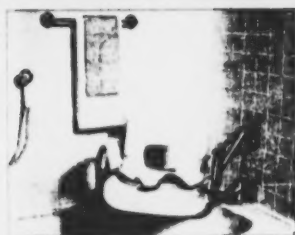
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B = both

? = non-distinct

* = in-state only

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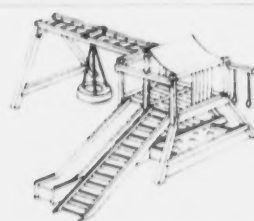
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- The challenge for state governments is to make sure that evolving systems of family support respond to the needs of all families — regardless of race, creed, economic status or ability/disability level. Today members of minority groups, including parents with disabilities, lack access to some programs.

- Service providers need to be educated about the new perspective of family-based support services. They need to learn to allow families to choose services and make their own decisions, and to encourage family members and people with disabilities to become informed advocates.

Family support is a valuable resource for parents who have a child with a disability. But because programs and eligibility requirements vary from state-to-state it can be difficult for parents to get the services and financial assistance they need.

P. C. C.

Information provided by Human Services Research Institute (HSRI), Cambridge, Mass. Special thanks to Valerie Bradley, president of HSRI.

Family Support Syndicate

The Family Support Syndicate is a nationwide network of grass roots organizations interested in improving family support services. Syndicate members share ideas, concerns and information about issues that affect people with disabilities and their families. Forty-one family support groups from 34 states currently participate.

Human Services Research Institute (HSRI) organized the syndicate.* Each month HSRI collects information on a specific topic from members of the syndicate. Topics range from "What is family support?" to "How can we pay for family support services?" HSRI distributes the information to all member groups.

The syndicate also holds teleconferences (complete with handouts) to provide direct communication between groups. Organizations that are not members of the syndicate can participate if they are interested in family support issues. Sixty groups registered for the most recent teleconference.

Urge your local support group to join the Family Support Syndicate. Contact Kerri Melda at HSRI, (503) 362-5682, for more information.

*A grant to HSRI for disseminating information will end on September 30th. HSRI will seek additional funding.

HSRI published information on topics addressed by the syndicate as three volumes — *What is Family Support? and Why Do We Want It?*; *What is Working in Family Support?*; and *How Do We Spread the Word?* Volumes cost \$12 each. Contact HSRI at (503) 362-5682 to place an order.

Exceptional Parent Back Issues!

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	June 1993	1992 Summer Program Awards and Commendations; Selecting a Seating System; Evaluating Feeding Concerns.	
	April/May 1993	1992 Summer Program Awards and Commendations; Making Your Home Work — Ramps; Guide to Summer Fun.	
	March 1993	4th Annual Mobility Guide; School Bus Safety; Finding Funding for Assistive Technology.	
	February 1993	Mainstreaming Contest Winners, 1992; Annual Income Tax Guide; Coping with Incontinence.	
	Nov/Dec 1992	10th Annual Computer Technology Issue; Best Technology and Everyday Life Awards, 1992; Estate Planning.	
	October 1992	Presidential Candidates Speak Out; Mainstreaming Contest Winners, 1992; Family Hall of Fame.	
	September 1992	20th Annual Education Issue; Mainstreaming Contest Winners, 1992; Victory for Mainstreaming; Annual Directory of National Organizations.	
	April/May 1992	Challenger Little League; Being a Father; Guide to Travel & Recreation; National Park Service's Accessibility.	
	March 1992	3rd Annual Mobility Guide; Maintaining Your Wheelchair; Children & the ADA; Van Lifts; State Accessibility Offices.	
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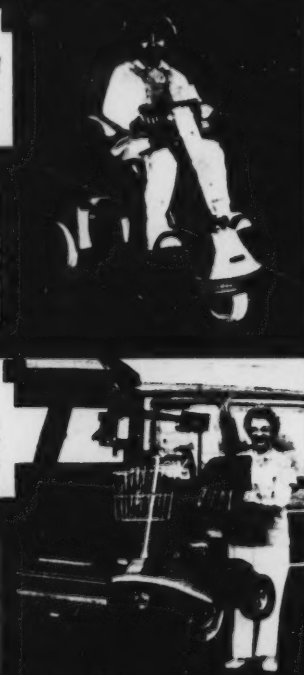
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FAMILY SUPPORT

continued from page 13

don't know everything and you should go ahead and accept this fact. I think that's why we refer to them as "practicing" physicians.

I hope you can find a good, family-centered physical therapist, occupational therapist, speech therapist and cognitive therapist (one or all) to help you learn to care for your child. Just being able to talk and cry (as I do) to the therapist about what your child can or cannot do is a tremendous help.

If you have therapists who are not doing what you need them to, change therapists! Remember, you are the center of the wheel, everyone else that sees you and your child is a spoke. Take charge! You're going to be the best advocate for your child. Take control and if it doesn't work for you, get the help that will work.

S.R.M
Alabama

Your life is of great importance to your child. You need to be strong for his sake. He will need all your love and patience.

My 10-year-old son has multiple physical and mental disabilities and is unable to talk. He has attended a school for children with disabilities since he was 18 months old. He loves school and is a very happy and easy-going child.

I still have to deal with doctors as my son needs their services. He sees an orthopedic surgeon, a neurologist and an ophthalmologist. They are unable to give me any prognosis. But you cannot give up on the medical profession because you need their help managing your son's present and future medical needs.

You live with the problem on a daily basis and you know your child better than anyone. You must not be intimidated by the doctors. If your son needs help, you must ask for it, even fight for it if you have to.

Please do not give up hope. Get whatever services are available in your area. If your son has a strong body and tries hard, then you need

to help him accomplish whatever he is able to do. Have your pediatrician refer you to a therapist.

You would also benefit from a parent/infant program. When my son was an infant, a specialist/teacher was sent to my home. She was a wonderful help to me as she suggested toys and activities that I could use to interest my son. You also need to get in touch with a parent group. It is of great benefit to know that you are not alone in your grief.

A.H.
California

Twelve years ago, I was a 22-year-old single parent who was told that her new and beautiful baby had cerebral palsy, a seizure disorder and profound mental retardation. Well, not only did we survive it all, but I have to say that mere words could never express the blessing this child has been to me.

My son, Jeff, spent four years in a wheelchair but can now walk. He still cannot speak, but he lets me know when he wants something. He is beautiful and precious.

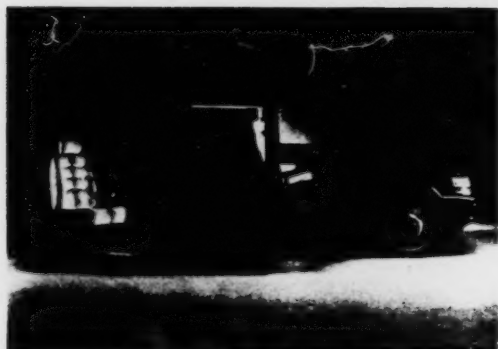
No matter how bleak things may seem at times, you have to believe in yourself and your child. My son will never read or write or even talk, but we have developed an unbreakable bond of love.

I think the most important thing you need to realize is that with children like ours, you can NEVER tell what they are going to be like as adults. You can, however, give your child all the love and encouragement he needs to push forward when he is ready. Accept him or her for who they are and love them for it.

One of the best things I ever did for myself was to join a support group. I didn't think I needed to, but I realized that I did need some emotional support. You should be able to find a similar program in your area. I learned to stop feeling sorry for the two of us and begin to look ahead at "what do I do now."

C.Y.
Pennsylvania

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Exceptional Parent • July/August 1993 45

Auto Industry Offers Incentives

Ever-improving technology in the automotive industry enables people with mobility problems to safely enter and ride in or drive cars, vans and light trucks. But modifications such as wheelchair lifts, hand brakes and raised roofs can be expensive.

Four automobile companies — Chrysler, Ford, General Motors and Volkswagen — offer programs that provide cash incentives or reimbursements to help finance the purchase and installation of adaptive driving aids and passenger equipment for people with mobility impairments. Most of the programs are available for a vehicle model year, which usually runs from October 1st to September 30th. Programs are up for renewal each year. Contact your local dealers to find out the status of their programs and ask if reimbursement and other benefits have changed.*



Program: Physically-Challenged Assistance Program (P-CAP), (800) 255-9877

Cash Incentive:

- \$1,500 maximum per vehicle toward the conversion of up to two new Chrysler full-size vans or wagons per model year.
- \$500 maximum each toward the conversion of any other new Chrysler vehicles, for up to two vehicles per model year.
- Vehicle must be converted within nine months of purchase or lease. Claim must be submitted within 30 days of conversion.

Resource Center:

- Provides information on 3,000 adaptive vehicle equipment makers, installers and trainers around U.S.
- Open to all consumers.

Other Features: Chrysler manufactures a front-wheel drive minivan. Conversion companies can lower the van floor and attach restraints so driver can remain in wheelchair. Modifications such as a platform lift or raised roof are not necessary. Maneuverability and overhead clearance are not compromised.



Program: Ford Mobility Motoring Program, (800) 952-2248, (800) TDD-0312 (hearing impaired)

Cash Incentive:

- \$750 maximum per vehicle toward the conversion of up to 10 new Ford, Lincoln or Mercury cars, vans or light trucks.
- Vehicle must be converted within 10 days of purchase or lease.
- On-the-spot reimbursement is available if claim form and paid equipment invoice are submitted to a local car dealer.

Resource Center: Answers questions and provides lists of nearby assessment centers and adaptive equipment dealers/installers.

Other Features:

- Free videotape provides an overview of driver/passenger assessment-vehicle adaptation process and shows examples of modified vehicles.
- Complimentary Ford Cellular Telephone. Requires a minimum of 121 days on Ford Cellular System, which is not available in all areas of U.S. Vehicle owner must pay service and usage charges. (Acceptance of free cellular phone is optional.)

* Factory-installed/dealer options and used or Fleet Program vehicles are not eligible. Funding from other sources, such as Medicaid or Rehabilitation Services, will not affect reimbursement from automotive companies.

continued on page 46



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Program: Mobility Program for the Physically Challenged, (800) 323-9935, (800) TDD-9985 (hearing impaired)

Cash Incentive:

- \$1,000 maximum per vehicle toward the conversion of up to 10 new GM vehicles per model year.
- Vehicles must be converted within nine months of purchase or lease. Reimbursement application must be submitted within three months of conversion.
- Modification of dealer demonstrator model or reinstallation of equipment from old modified vehicle is covered.
- GM Divisional incentives do not affect reimbursement.

Resource Center: Provides listings of adaptive equipment installers and driver assessment centers, wheelchair-compatible GM vehicles, organizations that offer transportation services and sources of outside funding.

Other Features:

- New vehicle and modification can be financed through GMAC in one transaction at the time of purchase.
- Complimentary 20-minute, open-captioned video, *On the Move Again*, describes how people with disabilities can become licensed drivers. It also shows vehicle modifications and adaptive equipment.



Volkswagen

Program: Mobility Access Program (for '93 vehicles purchased by December 31), (800) 444-VWUS

Cash Incentive:

- \$500 toward the purchase and modification of a new Volkswagen.

Note: Applicant must show proof of adaptive driving requirement — a photocopy of both sides of driver's license or the original paid invoice for installation of adaptive driving equipment.

- \$1,000 toward the purchase of EuroVan to transport driver or passenger who uses wheelchair for normal mobility.

Note: Must show proof of full-time wheelchair use — a letter from a physician stating that the buyer (or a passenger) uses a wheelchair for normal mobility or the original paid invoice for installation of a wheelchair lift on a new EuroVan.

- Proof and vehicle bill of sale must be attached to claim form.
- Cash incentive is available even if vehicle is not modified.

Resource Center: None, but consumers can call (800) 444-VWUS if they have questions about the program.

Other Features:

- New vehicle and modification can be financed through Volkswagen's credit company, VCI, in one transaction.
- Most side- and rear-mounted wheelchair lifts fit the EuroVan without vehicle modification. Ease of driving and parking is not compromised.
- Free promotional video about the EuroVan is available.

For more information about sources of funding and driver services for people with physical disabilities, contact:

American Automobile Association

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WE RECENTLY INVITED ALLIANCE FOR TECHNOLOGY Access centers to submit success stories describing individuals or families who have incorporated technology into their lives. This is *Exceptional Parent's* fifth installment of these stories.

In some stories, specific products illustrate the wide variety of technology tools available and represent a few of the many products demonstrated and used at ATA centers.

ATA Scrapbook of Success

Tooling up for success

Joe is 19 years old and interested in auto mechanics, farming and computers. He works part time from his home and attends Madison Central High School in his home district.

Our earliest recollections of Joe are as a five-year-old in what was then a segregated classroom for "primary educable mentally handicapped" students. For two years, Joe struggled with the early concepts of reading using traditional reading materials mandated by the Board of Cooperative Educational Services (BOCES) as modified by his teacher.

Joe moved on to the first computer introduced into that class in the form of an Apple II manufactured by Bell and Howell with virtually no software. Four years later, with the explosion of technology-based tools, Joe's teacher left BOCES to work with the Resource Center for Independent Living to develop the Techspress Program.

Techspress, the ATA center in Utica, N.Y., met Joe again when he was in a segregated high school classroom to which he was bused every day. Joe's teacher called Techspress after recognizing that Joe's educational abilities were hindered by the lack of appropriate resources. She did not know much about technology, but she knew there had to be a tool that could help Joe's visual perceptual skills.

Joe readily speaks about the frustration of not being able to read

his own handwriting. When Techspress was invited to the high school to see exactly what Joe was doing, he took us over to his Apple IIe computer and explained how he used it. He worked with his face about six inches from the monitor and moved through his word processor with great difficulty.

At the high school, Joe was successfully mainstreamed into science classes. He wanted to be mainstreamed into all of the classes and attend his home district school. To assist in this transition, Joe needed access to a computer at all times, for everything from taking notes and tests to drawing science graphs and writing English essays.

After discussing the options with Joe, we determined that he would need a portable word processor with large print on the screen and large print output. So Joe, his family, his teacher and Techspress began looking for something to meet those qualifications. We found a portable word processor/typewriter that had large print both on the screen and in print. Now it was funding time.

It took a full year of working with the Committee on Special Education to secure the funding for this device as well as an assurance that he could take it home with him and use it when he went back to his home district. Joe now attends Madison Central School and is exactly where he wants to be.

Untapped potential unleashed

From a parent at our ATA center in Honolulu, Hawaii: Our 18-year-old son, Glen, has a seizure disorder with mental retardation. For 15 years, 135 teachers, aides and therapists have worked with Glen, primarily in the areas of attending skills and challenging behavior patterns. The focus on everyday skills replaced efforts in academics five years ago. According to assessment teams, Glen's overall functioning was in the severely mentally retarded range.

Six years ago, Glen's interest in a borrowed Apple IIe prompted efforts to include computer work in



A computer is the key for promoting Glen's individual growth and exploring his untapped potential.

his IEP; however, this request was ignored. Six months ago, Glen had his first session with Aloha Special Technology Access Center, Inc. (ALOHA STAC). Two sessions later, the executive director of the center shopped, ordered, delivered and installed our son's Macintosh with an Apple IIe emulation card.

Today, Glen's attention span reaches five hours in one sitting at the computer. Mastery in using the mouse, opening and closing files, switching to Apple IIe programs and printing has given our son hours of enjoyment. One program requires 14 steps to get into, which Glen does with ease.

Our family delights in watching his recognition of letters and numbers increase and his eagerness to independently explore and learn new programs. Seeing Glen's cognitive skills develop in such a short time reinforces our belief that Glen has a lot of untapped potential. The key tool for promoting his individual growth is the computer.

The Alliance for Technology Access (ATA) is a network of community-based technology resource centers dedicated to providing access to the assistive technologies and related services that enable people with disabilities to achieve productivity, independence and success according to their individual needs and interests.

ATA centers serve people of all ages with disabilities of all kinds and have comprehensive, multifaceted programs that reflect their specific community needs, as well as local talents and resources. For more information about the ATA and the center nearest you, call (800) 992-8111 or (510) 528-0747.

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continued from page 51

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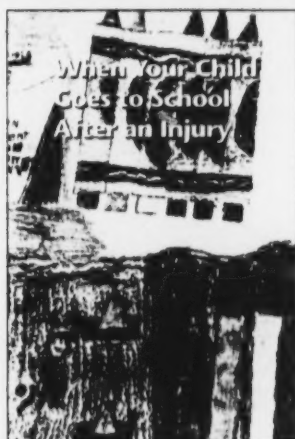
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by Marilyn Lash, M.S.W. Published by *Exceptional Parent* in collaboration with the Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center. ©1992 Tufts University. For information about purchasing *When Your Child Goes to School After an Injury* and *When Your Child is Seriously Injured*, see ad at right.

The following excerpt is from the chapter Preparation and Communication Between Families and Schools.

Preparing Your Family

Parents often say that arranging for special education was so time-consuming that they neglected others in the family. Siblings can feel excluded during the hospital stay and may even resent their lost time with and attention from parents. School is yet another change.

With all the attention on the injured child's return to school, it is easy to forget that it is also an adjustment for brothers and sisters. If siblings go to the same school as the injured child, there may be new responsibilities and pressures for them. Giving physical help is the most obvious need, but siblings are expected to give emotional and social support as well. This is not always easy. Siblings may be embarrassed by how their injured brother or sister looks or acts. They may feel torn between spending time with their friends and helping their brother or sister at school. They may resent the

extra attention given by teachers and friends to the injured child. Reactions vary widely. It is important to talk with siblings about their feelings and to be sure that each child receives attention and help.

Many times siblings find it difficult to ask for help and even feel guilty that they were not hurt. They may feel badly about having fun while their injured sibling is unable to take part. They may be confused about mixed feelings of anger and sadness.

... Parents suggest meeting with the teachers of all your children and the school social worker to explain what has happened. They can talk with siblings and give them extra time and attention and can alert you to changes at school. ... Sometimes reactions of siblings are delayed and the connection between difficulties at school and the accident is lost. Consequently, children may be punished without the cause of the problem being understood and discussed.

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and

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by Marilyn Lash

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Returning to school with new needs for education and physical assistance raises many questions and concerns for children, parents, classmates, siblings and teachers. Applying for special education and related services is complicated by the need to coordinate communication between hospitals, specialists, schools and families.

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J/A 93

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Communicating Partners: A Newsletter for Parents of Children Developing Language has been started to provide information to parents about how they can help their children become more socially interactive and communicative.

The information in the newsletter is based on more than 20 years of clinical research done at the Parent-Child Communication Program at the Nisonger Center for Developmental Disabilities at Ohio State University.

Each newsletter includes information on the stages children go through as they learn to communicate — social play, taking turns, nonverbal communication, language and conversation. Easy parent strategies for every stage of development will be discussed.

An important part of each newsletter will be parent questions, comments, advice and experiences.

For more information, write Communicating Partners, Parent-Child Communication Project, 207 McCampbell Hall, The Nisonger Center, 1581 Dodd Dr., Ohio State University, Columbus, Ohio 43210-1296.

AAAS

New Documentary Encourages Careers in Engineering

People with disabilities are uniquely ready to pursue careers in engineering, according to a new documentary now available to school counselors, academic advisors and others in positions to influence the academic and career choices of students.

The Problem Solvers, produced by the American Association for the Advancement of Science (AAAS) Project on Science, Technology and Disability, is a 27-minute documentary that focuses on successful engineers who have overcome a variety of disabilities.

The documentary was produced with funding from the NEC Foundation of America and the National Aeronautics and Space Administration. It features case studies and interviews with engineers which tell how individuals with disabilities have applied their abilities to meet the challenges posed by their disabilities.

The documentary draws from many different engineering specialties. Engineers describe their experiences in developing an interpersonal support network, overcoming attitudinal barriers, creating an empowering environment and using assistive devices.

The video and guide sell for \$20 each, plus \$4 postage and handling per order. *The Problem Solvers* (reference AAAS publication #93-15S) may be purchased by writing to AAAS, P.O. Box 753, Waldorf, Md. 20604 or by calling (301) 645-5643.

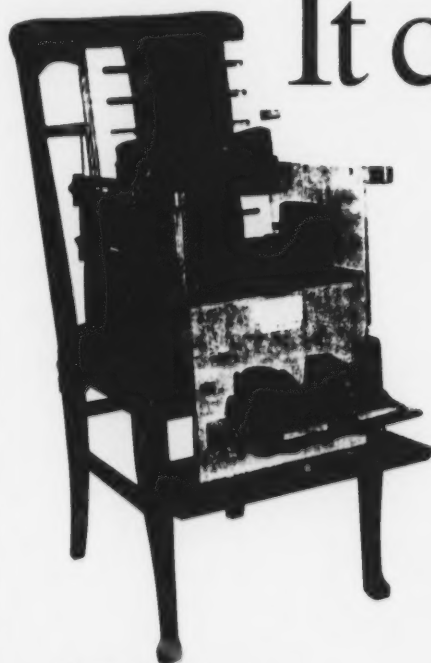
Booklet Helps Students with Disabilities Choose a College

How to Choose a College — Guide for the Student with a Disability is now available. This 16-page booklet is a joint publication of the HEATH Resource Center and the Association on Higher Education and Disability (AHEAD).

First published in 1986, *How to Choose a College* provides information as well as questions students should ask themselves and others while considering college choices.

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• **Lisencephaly Network**, Dianna Fitzgerald, 718 Autumn Ridge Ln., Ft. Wayne, IN 46804, (219) 432-4310.

• **National Psoriasis Foundation**, 6600 SW 92nd, Suite 300, Portland, OR 97223, (503) 244-7404, (503) 245-0626 (fax).

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Edited by Stanley D. Klein and Maxwell J. Schleifer, an *Exceptional Parent* Press publication published by Bergin & Garvey, Westport, Conn., ©1993. To order: *Exceptional Parent*, 1170 Commonwealth Ave., Boston, Mass. 02134, \$14.95 (plus \$3.50 shipping and handling).

The following was excerpted from the Introduction.

In 1972 *Exceptional Parent* magazine first published an interview with four college students, each of whom had a sibling with a disability. Families raising a child with a disability at home at that time did so in the context of very limited educational or therapeutic services for the child and little or no community support. Accordingly, each college student had grown up in a family setting where parents and other family members provided most of the care needed by the child. They did so in communities that were years away from being sensitized to current concepts of inclusion and community participation of children and adults with disabilities.

In those days when a child with

a noticeable disability was born, parents were often advised to institutionalize the baby. Professionals believed the parents would be assuming a terrible burden by taking the child home and that the rest of the family, and especially the other children, would suffer. Even though the professional literature was beginning to discuss positive as well as negative outcomes for family members when a child with a disability was raised at home, many professionals continued to believe it would be harmful to the family. ...

Despite the vast changes of the past two decades for children with disabilities and their parents and siblings, most of the issues discussed by the four college students in 1972 continue to be relevant to family life today. They are issues that deal with essential relationships between sisters and brothers, and children and parents. Although certain issues can have particular poignancy when one child has a disability or serious health problem, the issues of fairness, parental expectations, rewards and punishments, caretaking responsibilities, and negative feelings between siblings are common to all developing families. One issue, the role of straightforward communication within families, is a motivating factor for this book as well as for *Exceptional Parent* magazine's continuing attention to sisters and brothers and family relationships.

The participants' interview with *Exceptional Parent* was the first time they had ever discussed their sibling relationships with peers who had similar life experiences. Subsequently, the publication of the interview and a gradually growing professional literature stimulated similar group discussions. Today, the value of siblings of children with disabilities or special health care needs talking with one another, with parents, and with professionals is widely acknowledged.

Structure

The book is divided into five parts. In Part I, the interview with the college students is followed by an

article by Meyer Schreiber, one of the first professionals to write and speak about the needs of siblings. In Part II, there are eight articles by parents and one by a team of professionals. In Part III, there are seven articles written by siblings reflecting on their experiences. A series of case studies highlighting sibling relationships follows in Part IV. The book concludes with Part V and a series of brief articles written by children, first published in *Exceptional Parent*'s regular feature, *Family Album*.

Each article in this book was published in *Exceptional Parent* from 1972 to 1992. These two decades saw dramatic changes in community attitudes about people with disabilities and their families and in opportunities for children and adults with disabilities to participate in everyday community life. These changes have meant that families can look outside themselves for resources. There is now greater community understanding and appreciation of parenting with a family that includes a child with special needs. Still, parents' desires to meet the needs of all their children in constructive ways continue, as do those common everyday interactions between sisters and brothers about which parents wish they had more information, patience, and energy.

From this collection, it is clear that children, just like their parents, need accurate information about a sibling's disability presented with compassion and understanding. It is also clear that siblings benefit from talking with people like themselves who are coping with similar life experiences.

Overall, this reminds us, as stated at the end of the sibling interview: "We can learn and relearn by our willingness to listen to other human beings. ... As parents and professionals we need to be reminded by the inner strength of our fellow humans. We need to be reminded that a disabled child has siblings and parents and relatives and neighbors, each one can learn from the other."

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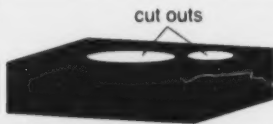
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A meal platform keeps the cup and plate stabilized.

Problem: During mealtime, dishes can slide around on the table or be too far away from the person who is eating.

Solution: A meal platform is easy to build and prevents the cup and plate from moving. It can also improve posture by placing the food at a more accessible height.

The following materials are needed: one large sturdy cardboard box with a strong, solid bottom; one bowl or plate with a top wider than its base or with an edge around the top; one cup with a top wider than its base; and contact paper.

Using a craft or utility knife, cut the box to a height that is comfortable for the person who will be using the platform. Cover the box with contact paper.

Cut a hole in the bottom of the box large enough to hold the bowl or plate. For example, a bowl with a 5-inch-diameter base and an 8-inch-diameter top will

need a hole about 7 inches in diameter. Repeat the second step, but this time cut a smaller hole that will hold the cup.

At mealtime, place the bowl or plate and cup in the prepared holes. The platform will both lift the bowl or plate closer to the user for better posture and easier spoon feeding and will hold the cup and plate so they don't slide around on the surface of the table.

It may be helpful to stabilize the platform itself by placing it on a rubber mat on the table or fastening it to the table with VELCRO™.

*Kathy Malcomson
 John Piccarella
 New York*

Problem: The Oregon coast is a beautiful place to run through the sand, pick up shells and explore. Unfortunately having a daughter who uses a wheelchair changed my perception of the coast.

Danielle's wheelchair was useless in the sand and she is too heavy to carry. She was easy as a baby, but as a six-year-old she was too much for me alone.

Solution: One winter, while pulling Danielle in the snow in a small plastic sled, I wondered how it would work in the sand. On our next visit to the coast, I found that it was the perfect solution. It glided on the sand and was easy to pull.

She could pick up shells and rocks and put them on the sled with her. Others who didn't want to carry their shoes or "findings" would make Danielle a deal to carry them.

She was even able to get

close to the waves, and the sled floated a bit on the water.

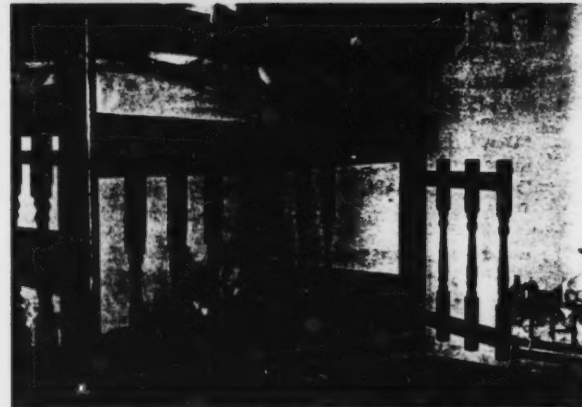
People would often look at us pulling her and shout, "Wow, what a great idea!"

I know that this is only a temporary solution. She

won't want to be in a sled when she is 16 years old, but at least we have a little more time to keep thinking. Until then, we all enjoy the coast.

*Diane Mitchell
 Oregon*

SUPER TIP



This special bed keeps children in bed at night and also makes a fun play fort.

Problem: My five-year-old daughter, Erin, has Angelman syndrome. A year ago, when Erin learned to climb out of her bed, all of our troubles began. She would not stay in bed. Some nights we were up until 4 a.m. trying to get her to stay in bed and go to sleep. Finally, after months of trying different techniques, she would stay and sleep in her bed, but only if one of us stayed with her until she fell asleep. This still occasionally took an hour. After five months of this, we had had enough.

Solution: The nurse at Erin's school had an idea for a special bed that children cannot get out of. We bought a very cheap bunk bed (even broken in spots) and my husband constructed a special bed. He put spindles around two sides of the bed from the top bunk to the bottom bunk and the other two sides were put against the walls. A door made out of the spindles was put on one side. Erin could not get out of this bed. We were scared she would hate it and we weren't happy with having a "cage" bed.

The very first time Erin was in the bed she loved it! It was like a play fort. She and my younger daughter go in there during the day and play. Since the first night she was in the bed, we have had no problems. She goes to sleep with no crying or fighting.

*Lisa Liesz
 Illinois*



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Hot water swirls and churns, limbs relax, movement eases. A child smiles. Soothed and buoyed by the bubbling warmth, he responds as his arms and legs are gently stretched, pushing against the flow of the water, relaxing back with it, each movement broader, smoother than the last.



Young bodies float in a broad expanse of bath-tub-warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex; laughter at splashes and water-antics; shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

The little boy described above does not wear a daytime brace to maintain his range of movement. Instead, once a week, he experiences the intense relaxation of the Hubbard tank. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more coordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

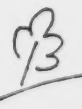
The young man in the therapeutic pool will also experience a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a movable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the children, when in the pool, to move in ways in which otherwise they cannot: if they cannot walk on land owing to poor strength or joint pain, they might be able to walk independently when in the water, or they might acquire real movement, instead of spasticity. Here, in the pool's supportive warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced - and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multi-faceted program at Berkshire Meadows, a private, non-profit residential school for children and adolescents who are developmentally delayed and multiply disabled. Nestled in the heart of the Berkshire Hills, the attractive and carefully-designed campus also houses several cheerful residences and a Learning Center equipped with state-of-the-art teaching aids. The program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of pre-cognitive, cognitive, pre-vocational and independent living skills. There is an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.



At Berkshire Meadows we believe that all children, no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

For further information, please contact: Ms. Gail Charpentier, Berkshire Meadows,
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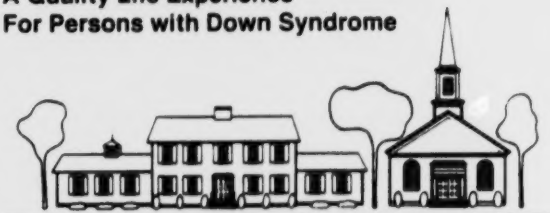
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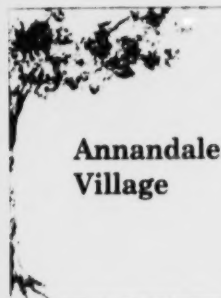
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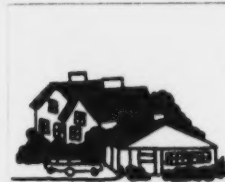


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Tube Feeding at Home

Tube feeding can provide an opportunity to strengthen the bond between you and your child. But be patient. Adjusting to tube feeding takes time. Don't try to assume all the responsibility for the feeding yourself. Let other family members learn to tube feed, too. Be patient as they learn the procedures and develop skills and confidence.

Because all children need to feel loved and secure, it is important to hold, cuddle and comfort your child even though he or she has a feeding tube. The older tube-fed child may be able to help with tube feeding or even carry it out independently in some cases. You should encourage your child to accept responsibility for as much of the feeding as he or she can handle. Sometimes it helps a child to practice tube feeding with a doll.

As you become more comfortable with the procedure, try to make tube feeding a routine part of family life. Some families prefer to tube feed the child during the family mealtime. Others choose to tube feed the child in private and then have the child join and socialize with family and friends while they are eating. You probably will want to experiment to see what works best and is most satisfying for you, your child and other family members.

If your child is old enough to respond, don't be afraid

to ask questions. For example, how does he or she feel about being with the family during mealtime? About seeing food but not being able to drink or chew and swallow it? Encourage family members and friends to discuss their feelings about eating in front of the tube-fed child. Open discussion of these issues will allow you to decide what will work best for your family.

Sometimes tube feeding is a temporary measure intended to supplement your child's regular diet because he or she cannot get enough nutrients from the regular diet. Encourage normal eating during mealtimes by timing the tube feedings so that they do not coincide with the family's eating schedule. This plan will allow your child to share mealtimes with the family as often as possible.

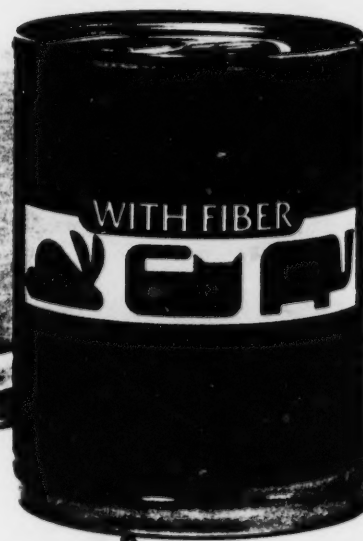
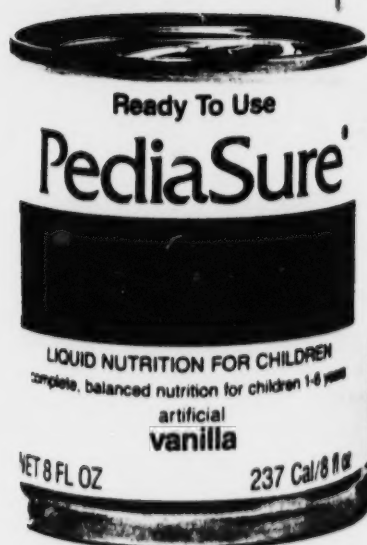
Be sure to find out about the variety of portable tube-feeding devices that allow a tube-fed child to move about freely. Try not to interrupt family trips and vacations because of the inconvenience that tube feeding represents. Treat your child as normally as possible.

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Spills and Thrills!

by Alice Wershing



Have you ever wanted to see how many dishes a tray could hold without worrying about spills and the ensuing mess? Try playing Stretch-Out Sam™ from Milton Bradley. The object of the game is to be the first player to put all of your dishes on Sam's tray. (A spinner determines the number of dishes each player must place on the tray.) Sounds easy, right? But if the spinner also points to "tipping" Sam, the player must lengthen Sam's arm by pressing a lever on his back. As the tray goes higher, it becomes harder to keep the dishes on his tray. If any fall off, the player must add them to his or her pile. When the game is over or if all of the dishes have fallen off the tray, Sam's arm is reset by turning a dial on his back.

Turning the dial to reset Sam's arm may be difficult for some players, so a larger grasping surface can make turning the knob easier. Add a short piece of plastic plumbing tube (1½ inches in length and 2 inches in diameter) around the knob. This tubing collar should be large enough to fit over the knob but still create resistance when turning it. To ensure a snug fit, it may be necessary to wedge some foam material around the knob while fitting the plumbing collar over it.

To make it easier to lengthen Sam's arm, add a short, L-shaped plumbing connector to the lever on his back. The diameter of the plumbing tube should also fit tightly

around the end of the lever. Be sure the tubing extends away from Sam's body to keep it out of the way when resetting his arm at the end of the game.

Some players may have difficulty spinning the dial, but mounting it onto a sturdy paper plate makes that easier. Depending on the needs of the players, any plate can be used, as long as it is slightly larger in diameter than the spinner. Players can hold the outer edges of the plate with two hands and tilt it to move the spinner. Players can determine the length of time for each spin to be sure that a random selection is made. Another option is to designate an additional person as spinner for the entire game.

The dishes included in the game are small and may be hard for some players to hold. Other players might have difficulty dropping them gently onto the tray. Playing in teams would allow each player to participate. One team member can be the "tipper" while the other team member adds the items to the tray. The team could also decide which items to put on the tray and how to place them.

Have fun, but don't tip the waiter!

Stretch-Out Sam™ is available from Toys R Us.

Alice Wershing is the Computer Resource Specialist and Toy Program Coordinator at the Disabled Children's Computer Group (DCCG): Technology Resources for People with Disabilities, 2547 Eighth Street #12A, Berkeley, Calif. 94710, (510) 841-DCCG.

Illustration by Kathleen Johnson Cox

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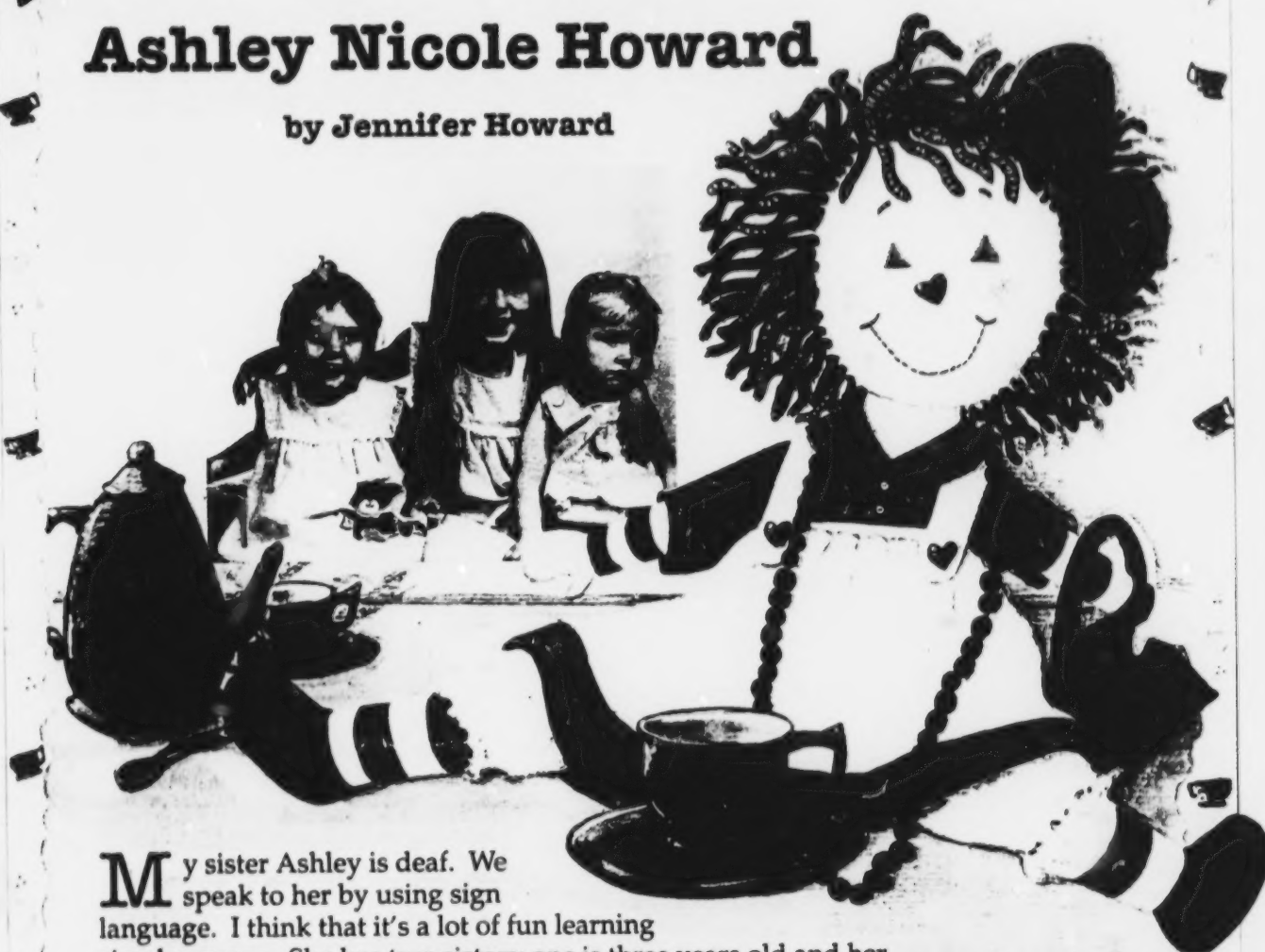


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Ashley Nicole Howard

by Jennifer Howard



My sister Ashley is deaf. We speak to her by using sign language. I think that it's a lot of fun learning sign language. She has two sisters; one is three years old and her name is Amber. I am her older sister. I am seven years old. My name is Jennifer. Ashley is five years old. She had nose surgery three times — once when she was four days old, once when she was four months, and once when she was eighteen months old. She had heart surgery when she was eight months old. She got a trach when she was eight and a half months old. She had a tube in her stomach. It left a mark that we now call a special belly button. She had already started to talk before she had the trach. We like to play chase, kitchen, house, store and barbies. She is in kindergarten. Ashley and I ride the bus in the morning and in the afternoon. I love Ashley and I know that she loves me too. We have a lot of fun together. The End.

Eight-year-old Jennifer Howard lives in Columbus, Ga., with her parents John and Karen and her sisters Ashley, 6, and Amber, 3. Jennifer just finished second-grade at Double Churches Elementary School. She is a member of the Brownies and her hobbies include reading, writing, drawing and computers. Ashley, who was diagnosed with CHARGE syndrome when she was three weeks old, is in the regular hearing impaired class at Key Elementary School. Amber attends St. Mark Nursery School. The three Howard girls are pictured above (from left to right) Ashley, Jennifer and Amber.

Illustration by Kathleen Johnson Cox



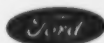
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² Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of purchase or lease. Ask your Dealer for complete cellular phone details.

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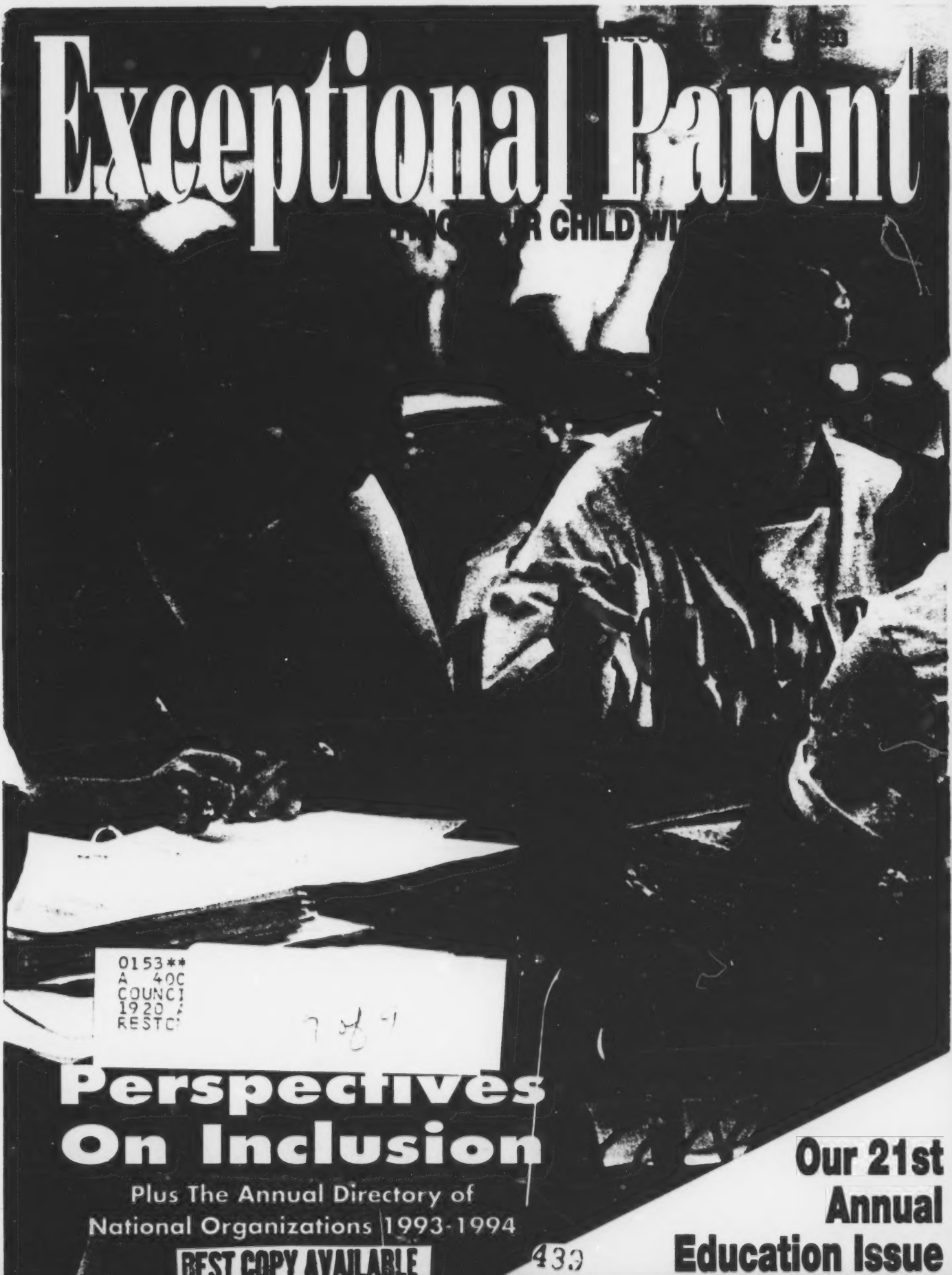
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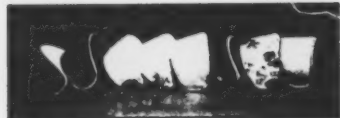
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Exceptional Parent

PARENTING YOUR CHILD WITH A DISABILITY

September 1993

Volume 23 Issue 7

FEATURES

- 15 1993 School Inclusion Award: Des Moines**
Parents, teachers and administrators collaborate to make inclusion work for all children.
- 17 Inclusion: A Child's Perspective** *by Anastasia Somoza*
"I like being in a regular class because I now have lots of friends."
- 18 Inclusion: A Parent's Perspective** *by Carlos Oberti*
A father explains that true inclusion benefits all children.
- 22 Inclusion: An Administrator's Perspective**
by Howard P. Blackman
A special education administrator shares his insights on inclusion.
- 25 Inclusion: Future Goals** *by Senator Tom Harkin*
Application of the Goals 2000: Education America Act to individuals with disabilities.
- 31 Parent-Teacher Cooperation—A Shared Responsibility**
by Priscilla H. Presley
How to foster a healthy relationship with your child's teacher.
- 64 Treatments for Attention Deficit Hyperactivity Disorder**
by Gregory S. Greenberg & Wade F. Horn
An excerpt from *Attention Deficit Hyperactivity Disorder*.
- 67 Residential Placement: Coping with Separation**
by Karen Cord Taylor
Finding the best placement and dealing with separation are difficult.
- 74 Effective Parent Advocacy: How to Take Charge**
by Helen Rader & Jennifer Simpson
Tips on how to advocate.
- 78 A Place in the Dugout: Family Mainstreaming in a Rural Community** *by Sonya Smith*
Eight-year-old Brian joins a T-Ball team.

DEPARTMENTS

- | | |
|-------------------------|---|
| 4 Editor's Desk | 83 Informational Forum: Networking |
| 6 Family Support | 92 What's Happening |
| 29 Media | 96 Children's Page |



Page 17

Annual Directory of National Organizations 1993-1994



Page 18

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EDITOR'S DESK



Stanley D. Klein Ph.D.

Welcome to our 21st Annual Education Issue which includes our Annual Directory of National Organizations. This issue is the first issue for our new team in New Jersey. As I announced in the July/August issue, our publishing office is now in Hackensack, New Jersey (120 State Street, Hackensack, NJ 07601), under the direction of Joseph M. Valenzano, Jr. Our editorial office remains in Boston. In this issue, you may notice some improvements in the design of the magazine. There will be more in the coming issues. Please let us know your comments.

1993 Inclusion Award to Des Moines

Congratulations to the Des Moines, Iowa, public school system—the 1993 winner of Exceptional Parent's Inclusion Award (formerly called the Mainstreaming Award)! When we called to inform the fine group in Des Moines, they were battling the tragic floods of the summer. We are hopeful that all our readers in communities hit by the floods are able to begin the new school year with hope for better weather and a relatively calm school year.

Perspectives on Inclusion

Anastasia Somoza, Carlos Oberti and Howard Blackman all discuss inclusion. The nation first met Anastasia on national television when she questioned the President and on the cover of our March issue. Carlos Oberti is a courageous parent who has fought hard for his son and for all children. Howard Blackman is a dedicated special education administrator who has championed inclusion for many years. Senator Tom Harkin also discusses inclusion as it relates to planning for the future of public education.

Sometimes, parents need educational choices that go beyond the public school system and the wonderful possibilities of inclusion. Karen Cord Taylor describes the process parents go through once they decide to place a child in a residential setting.

Two articles, "Parent-Teacher Cooperation" and "Effective Parent Advocacy: How to Take Charge" offer practical suggestions for parents. "A Place in the Dugout" describes inclusion in the community.

Directory

This year's Annual Directory has been revised so that more information can fit on fewer pages. Nonetheless, we have tried to include every national parent organization and have contacted each one to make sure the listings are correct. Whenever possible we have added fax numbers. If there are any omissions, please let us know.

Traveling

One of our goals for the coming year is to meet more readers in person. We will be traveling and attending more meetings because we are eager to receive feedback from our readers everywhere.



Cover

Economics class. Todd Martz shares a thought with fellow classmates at Wasson High School in Colorado Springs.

Photo by Stegner Portraits

Exceptional Parent

Parenting Your Child With A Disability

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Vicki Bertoldi,
Parent

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Letters to the Editor

Support for Placement Decision

I want to thank you for printing my letter, *Emotions Involved in Residential Placement* (Parents Search, June 1993).

I have already received responses and I feel very good knowing that there are other parents out there dealing with the fact that their child is in residential placement and they feel the same pain, loss and other emotions that I feel.

Up until now I have felt very much alone with my feelings and emotions since my son has been in placement for the past two years, but reading these letters has helped me not to feel so alone and isolated. It has also given me the strength to try to form a support group in my area for parents who have children in residential placement or parents who have children with mental retardation, autism or other disabilities.

Thank you, *Exceptional Parent*, for being a truly exceptional and invaluable magazine for parents of children with disabilities. Keep up the wonderful work you are doing.

V.S.
New York

Parents Need Choices

Thank you so much for an editorial (Liberty and Choices for All, June 1993) that shows you understand that residential placement of a child with special needs does not equate with a lack of love, concern or support on the part of the child's family.

Choices are what parents have fought for over the years. That's what IEPs are all about. Children with disabilities are individuals first. Family needs are also unique to each family. It is unfair of other parents or professionals

to presume to know what is best for my child or our family, especially those who have never even met us!

Please continue to represent the needs of all families and individuals with special needs. Our choices are often difficult and we don't need criticism from those who don't know us or our children. Keep up the good work, *Exceptional Parent!*

B.A.
Illinois

Blessed and Befuddled!

I am the mother of an exceptional child, Jordan Amanda. She has brought unspeakable joy and character into our lives. Our love for her knows no boundaries.

So, I'm wondering if any of you "exceptional" parents out there have been as befuddled as I. Befuddle means "to confuse" and that's just what I am — confused about the way our "wonderful" system works.

Jordan is 19 months old and has a physical disability. As for cognitive disabilities, they don't know yet as she is still too young to assess in that manner. They have labeled her as having a non-progressive encephalopathy.

Anyway, we know God doesn't make mistakes and love her as is. The mistake lies within the fact that we have been battling with our insurance company for almost one year because they say it is NOT medically necessary for Jordan to receive physical therapy — the only intervention TWO pediatric neurologists have prescribed for her.

I just want to know if any of you have experienced this horrendous battle. If so, please contact me and let's share stories! It's easier to fight a battle if more people come together and fight as a team.

Let's do this for our children! Who knows, I bet we could get on the *Oprah Winfrey Show* and receive national attention! May God bless and strengthen all of you!

J.C.
Missouri

Canadian Exceptional Parent?

When I lived in the States, I received *Exceptional Parent*. Recently I moved to Canada and was wondering if you knew of a similar publication for Canadian citizens.

Although many of the practical tips, emotional support and other articles are pertinent to all parents of children with disabilities, many references to legislation and financial assistance are particular to the United States. I am trying to find a publication with similar content with a Canadian angle. Any information you can give me would be helpful.

M.M.D.
Ontario, Canada

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We welcome all contributions to **Letters to the Editor**. Please send your questions, ideas and responses to: **Letters to the Editor**
Exceptional Parent
1170 Commonwealth Ave., 3rd Fl.
Boston, Mass. 02134-4646.

Parents Search

Single Parent with Disabilities

I am a single mother raising a seven-year-old son who has autism, ADHD, mental retardation and delayed speech. He has been in a residential center for the past year, but he will probably return home by October.

I also have disabilities, including learning disabilities and chronic back and knee problems. I don't drive and I feel very isolated because I don't have many friends. I am looking for other people for friendship and/or support.

*P.D.
Ohio*

Adaptive Bike Cart

Several years ago our daughter who has multiple disabilities began joining the rest of the family on bike rides in an infant seat. This was a very positive experience, especially because was difficult to find a recreational activity we could all enjoy together.

She is now four years old, weighs 35 lbs. and can no longer safely ride

with us in her seat. We are searching for a company that makes a bike cart she could use or is willing to adapt a cart to our needs.

If anyone has suggestions for finding a long-lasting, affordable bike cart or wants to join us in pursuing this, please contact us.

*E.L.S. & D.S.K.
New Jersey*

Puberty and Autism

I am the parent of a nine-year-old who has autism. She is approaching puberty and I am at a loss as to what I am going to do. It took us six years to get her out of diapers. She is a great sleeper, but she usually wakes up naked in the morning, no matter how late I check on her at night.

I am looking for other parents of girls with similar behavior problems to share their experiences. I am very apprehensive about the onset of her menstruation. Any help would be appreciated.

*P.K.
New York*

Insensitivity of the Cornea

Our five-year-old son was born with VATER syndrome. Although we were fortunate enough to find a VATER support group, he developed another problem three years ago. He has insensitivity of the cornea (very little feeling in his eyes). Since that time, we have discovered that this does occur in people who have VATER, but it is very rare.

We are searching for anyone who may have this eye condition. The condition was initially misdiagnosed as herpes of the eye. We would appreciate any information on this subject.

*C.B.
Florida*

Hydrocephaly

My three-year-old son, Jason, was diagnosed at birth with hydroncephaly. He has no gross or fine motor skills and no head control. He is considered deaf and blind. He has a seizure disorder for which he takes Depacote and Diazepam, but his seizures are still not controlled. At age two, he underwent

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surgery for a shunt.

Jason doesn't drink liquids and has recently quit sucking bottles. He is spoon-fed pureed foods and yogurt with milk. Because he doesn't get enough fluids, he also has constipation.

Jason was not expected to live beyond infancy. He has many problems, but that's Jason and we deal with them. People always ask how we handle it and I reply that we have no other choice — we do what we have to do. Every parent of a special child deals with their child's disability the best way they can, day by day. We can't look too far into the future for fear of what we might see.

Jason's life expectancy is short. I am happy to have whatever amount of time he has on this earth. What I fear most is the day that he becomes too much for me to handle. I pray that day never comes.

I would like to hear from other parents of children with similar difficulties.

R.F.
Louisiana

Cerebellum Hypoplasia

We have a 19-month-old son who was diagnosed with cerebellum hypoplasia. The vermis is unaffected and the left lobe is slightly smaller than normal, but the right lobe is severely affected.

We were very fortunate to get such an early diagnosis. Therapy began immediately and our son has progressed beyond what was expected of him. His muscle tone has improved dramatically — he sits, crawls, climbs stairs, cruises around furniture. His therapist is now working on his standing alone, but there are very obvious balance problems. He also has other developmental delays, in addition to visual problems.

Other than the neurologist who gave us the original diagnosis, the medical professionals involved have never dealt with this disorder and are unable to answer questions and concerns that we have. I would really appreciate hearing from parents of children with this disorder to discuss some behavior problems that have recently become a concern to us.

J.K.
New Brunswick, Canada

Editor's Note: For more information on rare disorders, contact the National Organization for Rare Disorders (NORD), 100 Route 37, P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518.

Cytomegalovirus Infection

I am a home-based family education instructor currently working with a family who has a 13-month-old son with cytomegalovirus infection. He was born one month premature with a low birth weight and has hearing and visual impairments and mental retardation. His gross and fine motor skills are delayed, as is his speech, although he does coo and babble to some extent. He can roll over and scoot himself around on his back. But when he is put in a sitting position, he will stiffen and arch himself back. He can also pull himself to a standing position by holding onto the side of his playpen.

Recurring ear infections and upper respiratory infections have been the main medical issues. He does have an enlarged spleen and liver, but according to his doctor they are both going down to their normal sizes.

In the upcoming school year, the child will attend an early intervention program. Between now and then, the family and I will work with him in various areas as suggested in his inter-family service plan. We would like to correspond with others who have a child with this type of infection.

C.B.
South Dakota

Parenting Two Children with Developmental Delays

Our eight-year-old son, James, and our five-year-old daughter, Jessica, are both labeled only as developmentally delayed. These are the only two children that we have.

They are both in the moderate developmental range, at about a two-year-old level, although James is more involved. Neither is potty-trained. They also have some behavior problems which include biting and pinching, but they are very social (loving and hugging). James now takes Dexedrine which seems to help. Both are exceptionally beautiful children and look very normal.

James seemed to develop normally until about six months of age when he

didn't turn over or sit up. He walked at 17 months of age and he now talks in one- or two-word phrases. He is low-toned in his upper body and he has no nystagmus. He receives occupational, physical and speech therapy. He is in a regular K-1 classroom with the help of an aide.

Jessica developed normally until she was about a year old. She walked at 18 months of age. She has nystagmus and she uses three- or four-word phrases. She receives speech therapy. She is not on medication, but her behavior has improved since James has been on medication. She is in a regular preschool class with the help of an aide.

We have been to pediatricians, neurologists, geneticists, bone specialists and a behavior pediatrician. Both children have had EEGs, MRIs, blood work for genetics, etc. The only thing we have been told is that both EEGs were abnormal but in different areas of the brain for each child. MRIs and genetic test results were normal. We were told that their mental retardation is probably genetic since both children are involved.

We would love to hear from professionals and families who have children with similar characteristics or more than one child with disabilities.

J.A. & B.A.
Kentucky

Wide Shoes

We have enjoyed, and benefitted, from the Exceptional Parent for many years. However, we have a rather mundane question. It is: "Our 30 year old daughter with Down Syndrome requires a 4 (or possibly a 4 1/2) WIDE in a dress shoe. These are available locally only in children's shoes and a source is desired for adult shoes.

DMG
Washington

Poland's Anomaly

I am writing to get information on Poland's Anomaly. My two-year old grandson has this. He has the absence of the pectoralis major muscle and syndactyly.

We would like to visit with people who have this and have had surgery to correct both or one problem. So far we haven't found anyone who has heard of this problem.

ND
Oklahoma

Parents Respond

Living with a Terminal Diagnosis

From M.L.B.'s Parents Search, June 1993: "My 11-month-old daughter, Erica, was recently diagnosed with lissencephaly. Is it true that her life expectancy is three years? Her therapy and stimulation classes take up so much of my time that if she dies before my time comes, what will I do? How do parents go on from there? How do you go on living day to day with a smile on your face let alone in your heart?" The following excerpts are from responses to M.L.B.

I, too, have a daughter with lissencephaly. I first would like to say that there is no life expectancy age which is set in stone for these children. Our family is connected with The Lissencephaly Network, Inc. There are children as old as 12 who are in the Lissencephaly Network and one of my daughter's doctors knows of someone with lissencephaly who is over 20.

We have met a few families with "Liss Kids" and have learned that there is a very wide range of the severity of disabilities among these children.

None of us knows when, or if, our precious child will be taken from us, but please don't be overly fearful that it could be "today." In doing so, you could lose time that might have otherwise been joyful for both you and your daughter.

Keep your fears as far in the back of your heart and mind as you can. Rejoice and praise all of her accomplishments. As trivial as they may seem to others, they are huge stepping stones. It also helps me a lot to talk openly about my daughter's disabilities with family, friends and co-workers.

G.L.L.

Minnesota

I read your letter with great empathy. While I am completely unfam-

iliar with lissencephaly, I have thought and felt many of the things you put in your letter.

Our oldest child, Emily, died four years ago from cancer. I had 13 months between the time she was proclaimed terminally ill until her death. I spent most of every day caring for her and, like you, I couldn't imagine how I would fill my days after her death.

I doubted my own strength and couldn't imagine how I would ever cope with her eventual deterioration and the pain that I feared she would have. I wanted to pour everything I had into her and at the same time actually feared that I'd go crazy. I knew that I could hold myself together while she was alive, but I remember wondering which institution they would cart me off to after she was gone. I expected to lose it badly when I lost her!

I wanted to give her time and attention. At the time of her original cancer diagnosis, a big part of me died. I stopped planning for her future and my short-range plans seemed so empty.

We put up a big fight with seven operations and chemotherapy, but we lost the fight. Emily died at age 12. The grief process hasn't gone as I had feared. You can't plan your grief! Stuff that I thought might be horribly painful wasn't so bad and some things that probably shouldn't have bothered me really did. Grief takes time. Time doesn't heal, but it does anesthetize. I cry sometimes about Emily but now I can also think about her and smile.

Anticipatory grief is weird. I did a lot of mourning and grieving while Emily was still alive. I thought maybe this would make the post-death grief a little easier, but it didn't. No matter how prepared you are, losing a child HURTS. All situations are unique, but if I have any advice for you, it is to love your kid like crazy while you've got her and do whatever you need to do to survive emotion-



Chairman of the Board.

That's my son Jedidiah. He's the reason I started Special Designs Inc. You see, as a parent of a disabled child, I had a lot of trouble finding furniture to fit my son's special needs. Furniture that's durable and sturdy, easy to adjust and easy to take along to a restaurant or to Grandma's. Furniture that looks like it belongs in a home--not in a hospital.

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-Peter Quense

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ally. Whatever you're feeling is okay, even if it doesn't feel that way.

B.M.
New York

Big Diapers!

From G.M.F.'s Parents Search, June 1993: "Diapering a child with multiple disabilities becomes a challenge after the child outgrows toddler-size diapers. The ideal diaper for her has been the disposable 'pull-up' style. However, I have not found a replacement diaper for an individual who weighs more than 50 pounds. I would like to keep my daughter in this style of diaper". The following excerpts are from responses to G.M.F.

I am a 22-year-old male with moderately severe cerebral palsy. As a result of my CP, my ability to control my bladder is severely impaired and it is necessary for me to use a disposable undergarment. Currently I use the Attends Plus, which is a diaper-style brief. I have found these to be very effective; however, I require assistance getting them on and off.

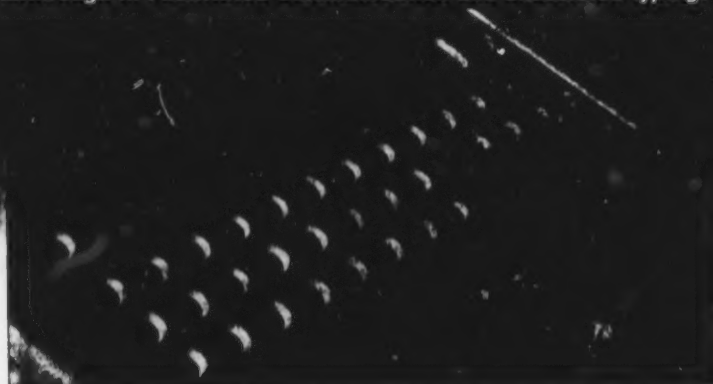
I too believe that a "pull-up" style undergarment would be the most suitable for my needs. However, I, like you, am not aware of a pull-up style undergarment being made in sizes larger than those for toddlers. Personally, a pull-up style undergarment would allow me greater independence, as I believe I could get them on and off myself.

I have written a letter to the chief executive officer of the Kimberly-Clark Corporation, the manufacturer of Pull-Ups, explaining the need for pull-ups in larger sizes. Kimberly-Clark also makes the Depends line of products for adults with incontinence. I would strongly encourage you to also write him. Maybe if they realize there is a demand for the Pull-Ups in larger sizes, they will produce them. The address is as follows: Wayne R. Sanders, Chief Executive Officer, Kimberly-Clark Corporation, 545 Carpenter Fairway, Suite 1300, Irving, Texas 75062.

B.A.P.
Pennsylvania

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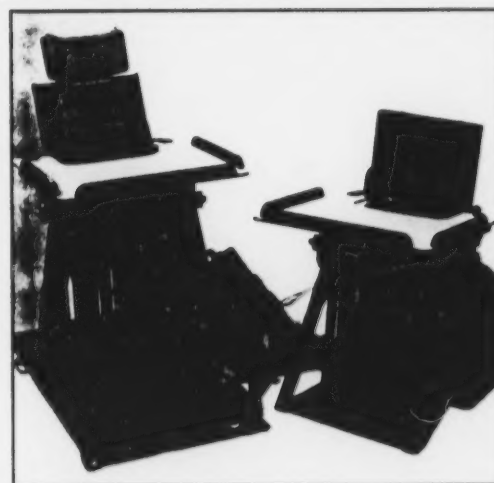
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My 12-year-old son, Ross, has autism and mental retardation and is incontinent, although he is making progress. For five years, I have used Nikky All Night Pants (all the time). They pull on like regular underpants and contain an all-cotton center padding that holds about one cup of liquid. They come in sizes 3 (34 lbs.) to 14/15 (93-110 lbs.). Ross still wears the 10/11 size because he is very slender with small hips.

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and dryable on the gentle cycle. The outer shell is made of Nikky's patented 100 percent cotton, waterproof material. These are absolutely wonderful!

My current source for these is Baby Works, 11725 NW West Rd., Portland, Ore. 97229, (800) 422-2910, (503) 645-4349. Other readers may know of more stores that carry them. I discovered an advertisement for these in an Exceptional Parent issue about incontinence products!

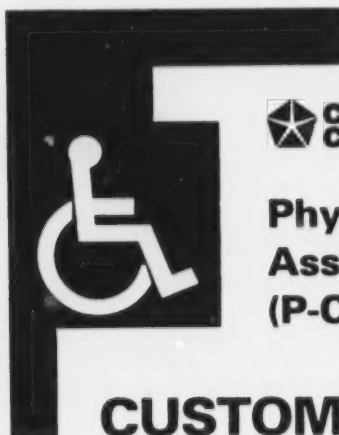
A word of advice: Turn them inside out for washing. If they are soiled badly, rinse before washing. They take a long time to dry, so purchase at least three.

C.M.
Texas

Activities to Help Kids Accept Students with Disabilities

From A.H.'s Parents Search, June 1993: "I have a brother with attention deficit disorder. I have seen a lot of discrimination at my middle school. Next year I am starting a club called Stop DADK (Stop Discrimination Against Disabled Kids). Does anyone have any ideas of activities this club could do and how you can help people accept kids with disabilities?" The following excerpt is from a response to A.H.

I applaud your motivation to educate your peers in school about kids with disabilities! I am a school social worker in a private school and I work with kids of all ages who have mental retardation, autism and behavior problems. As a social worker, I have the benefit of working with the families of kids

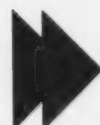


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Parents Search and Respond is an opportunity for our subscribers to get information from parents about their practical experience in handling the everyday problems of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Anyone who wishes to submit or reply to a letter in *Parents Search* or *Respond* should write to:

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1170 Commonwealth Ave., 3rd Floor
Boston, Mass. 02134-4646.

Please indicate whether it is a **search** or **response** letter and in which issue the original letter was printed when addressing a reply. All responses will be forwarded and may be published in our *Parents Respond* column.

For technical information about a disability, we encourage you to contact **NORD** (P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518).

with disabilities. I have found working with the siblings of these kids to be quite rewarding as well.

I have some suggestions for you about programs you and your group may wish to pull together:

- **Sibling Day** — A day off from school for the siblings to go to their brother's or sister's special school to learn about their educational program.

- **Disabilities Awareness Activities** — Choose activities designed to help kids learn what it is like to be disabled. These activities include learning about hearing test procedures, hearing aids, sign language, Braille, "trust test" with a blindfold and occupational and physical therapy equipment.

- **Sibling Support Group** — Start a group for kids with siblings with disabilities. Create a safe place to discuss the challenges they face living with a sibling with a disability.

- **Buddy System** — If you have kids with disabilities attending your public school, pair up someone with a kid with disabilities so there will be someone there for support and friendship.

- **Field Trips** — Take a field trip with a teacher or a group of friends and parents to a facility that serves kids with disabilities and take a tour.

- I have lots of references for books and articles to read and activities to do. Please write me for further information and I would be happy to send you some. (Laurie L. Rosen, MSW, National Children's Center, 6200 Second Street NW, Washington, D.C. 20011)

L.L.R.
Washington, DC

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(revised edition)

by

Karen Levine, Ph.D., *Director of Psychology*
The Children's Hospital, Boston, MA

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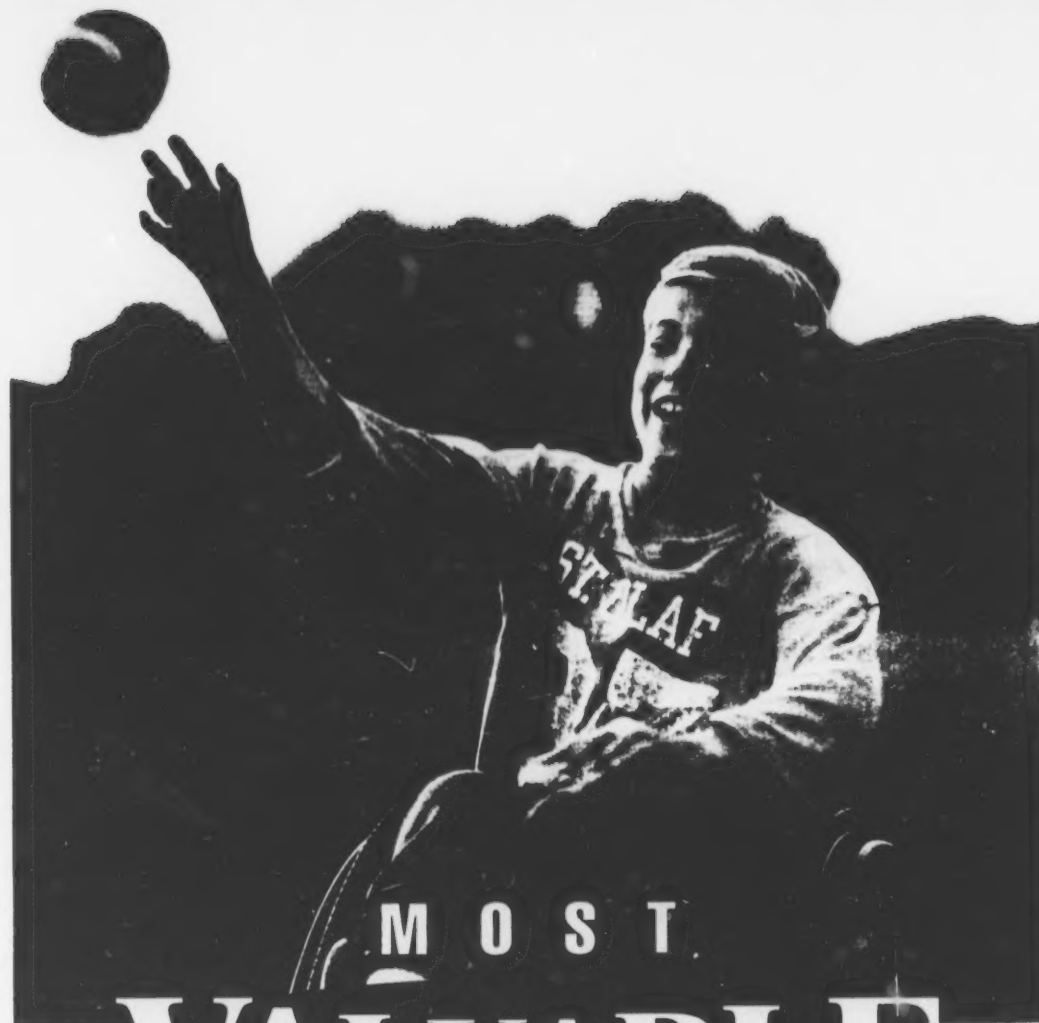
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Dorothy Campbell, second grade
teacher at the Rice School.

"The first time I saw her performing on stage with the rest of the kids, just to see her—she had her own little spot doing what a typical kid should do—it was very touching."

Deb Allison, parent of a
special education student.

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Dena Goplerud, parent of a
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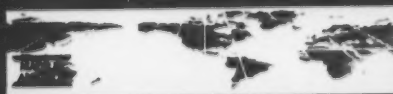


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A Child's Perspective



Anastasia Somoza, who has cerebral palsy, appeared with President Clinton on the cover of *Exceptional Parent* magazine last March. On national television she asked the President to help her sister, Alba, to be included in regular education classes. She testified earlier this year at a congressional hearing for reauthorization of the Technology-Related Assistance Act.

My name is Anastasia Somoza and I am nine years old. I live in New York City and go to school at P.S. 234 in Manhattan. I am in a third grade class in general education. I have a paraprofessional at school to assist me.

I have cerebral palsy and use a wheelchair. I also have a walker and a stander. I use a computer to help me with school work and special software. I wear braces on my legs to help keep them straight.

I like being in a regular class because I now have lots of friends. As my friends live nearby, they come over to my house for play dates and even sleepovers. At my old school, my friends lived too far away and they never came for play dates. We could not go to their house either because we do not have a car. All the kids at my old school were disabled and it was hard for their parents to bring them to my house.

My best friend at school is called Natalie. She is not disabled. She helps me with lots of things, and she plays with me at recess time. I am the only one in my class who cannot walk but that's okay. My friends push me around.

I have a twin sister who goes to the same school, but she is in a special class. She uses a computer to talk, and a different computer to do her studies. She also uses a wheelchair and a stander. She is very smart and I hope she can soon be in a regular class just like me. Thank you.

Anastasia Somoza and her twin sister, Alba, are now both in regular public education classes.

A Parent's

Carlos Oberti has spent three years fighting for public school inclusion of Rafael, his eight-year-old son who has Down Syndrome. In 1990, Clementon (N.J.) School District officials refused to educate Rafael in regular classes because they felt that Rafael's disabilities would keep him from benefiting from placement in a regular classroom. The Oberti's lost a local court case against the school district, then won in Federal District Court. The school district appealed to the U.S. Court of Appeals for the Third Circuit in May, 1993. The appeal failed. Representing the unanimous opinion of the Court of Appeals, U.S. Circuit Court Judge Edward R. Becker wrote:

We construe IDEA's mainstreaming requirement to prohibit a school from placing a child with disabilities outside of a regular classroom if educating the child in the regular classroom, with supplementary aids and support services, can be achieved satisfactorily. In addition, if placement outside of a regular classroom is necessary for the child to receive educational benefit, the school may still be violating IDEA if it has not made sufficient efforts to include the child in school programs with nondisabled children whenever possible. We also hold that the school bears the burden of proving compliance with the mainstreaming requirement of IDEA, regardless of which party (the child and parents or the school) brought the claim under IDEA before the district court.

In April 1993, Mr. Oberti spoke to educators at a colloquium on inclusion at Keane College of New Jersey School of Education. The following article is an adaptation of his speech.



Inclusion or Mainstreaming

In our experience, mainstreaming was merely placing a child with special needs in a classroom with regular peers. In contrast, inclusion provides teachers and students with tools needed to help children—including children with disabilities—to learn.

As parents, we are very much aware of the differences of our children. We are the first ones to know when a child is different and we are able to go through the stages of coping with that fact. When children with disabilities get to be of school age, it is very clear to us whether or not they are going to learn at the same speed as their peers. That is why mainstreaming alone did not work for our son. The expectation was to physically include him without addressing his special needs or the needs of his teachers. This is why I suggest we speak of "supported inclusive education."

Attitudes

To have a positive attitude we have to start by accepting the fact that we are not created equal. Each child has his own rate of development and deserves the opportunity to be exposed to a healthy learning environment. Educators—perhaps bureaucrats more than educators—have come to the realization that grouping children using a perceived notion of learning speed or intelligence test scores does not work. Evaluating with standard test scores is easy because tests are mathematical and fit well with classifications and labels—but they do not work.

Skills for Inclusion

Educators do not need to go through extensive training sessions and hundreds of hours of planning to make sure they cover every possible situation that ultimately will never arise. Due to the fact that there are as many ability levels as there

Perspective

are students, it is impossible to have an exact prescription for all of the students. This is an asset because we can adapt the available resources to meet changing requirements.

Need for Special Educators

Inclusion does not do away with special education teachers. Nothing can be further from the truth because special educators are a key part of educating differently-able children in inclusive environments. They are needed to work with the regular teachers to exchange ideas, create strategies and measure progress.

Benefits to All Students

Inclusive education can benefit all of the students and all of the teachers. Children with special needs learn to cope with their differences. They learn via the oldest and most primary form of education: imitation. They imitate speech; they imitate behaviors and they adapt to the social requirements of group interaction. How can we expect children with disabilities to become contributing members of society if we isolate them from children without disabilities for 13 years of school life?

All children benefit from being in an inclusive environment by learning to interact with all members of society regardless of their differences. They get an early exposure to attitudes and behaviors contrary to the harmful prejudices that some adults have. Through helping one another, they get a sense of unity and cooperation. They learn about social responsibility, caring and team work. They receive the kindness and friendship that all people, including those with special needs, have to offer.

Teachers learn from the challenge—from the creative demand that enhances their ability to teach. They learn from watching the students interact, which in turn allows them to discover the abilities each one of them has to offer. They learn about the hearts of the students. They get the opportunity to teach values such as kindness, generosity, sharing, friendship, loyalty, leadership and responsibility. Most of all, they provide opportunities for all to build self-esteem.

Self-esteem

To me as a parent, the most important issue of inclusion is



self-esteem. We must realize that many of the social problems our society faces today are the result of poor self-esteem in individuals who never had the environment or the opportunities to develop a healthy appreciation of themselves.

Good self-esteem at school age allows children to believe they can do things well. It gives them the assurance that if they dare to create new things they have a chance to succeed. If we group children with disabilities together, they

will surely see themselves only in their peers and are likely to learn inappropriate behaviors from each other.

With inclusion, we are placing children with special needs in the regular classroom, giving them the opportunities they deserve and allowing peer modeling of appropriate behaviors. We are subconsciously letting them know that they are equal to any other human being and capable of meeting our expectations.

Expectations in a non-inclusive environment tend to be low and the possibility for a child to get out of that self-perpetuating environment is often slim—provoking an endless chain of placements that often taxes society. When a child is given the opportunity and presented with the challenges of self help, he is far more likely to become independent enough to lead a productive adult life without continuing to tax society.

The social and educational implications go beyond the child with special needs. They surely affect every family member. Separating children of the same family often means shipping the child with special needs to a distant location making the possibility of a brother helping a brother or a brother helping a sister impossible. It makes the children without disabilities in the family feel as if they are different, and implies that they have to hide the fact that they have a brother or a sister with special needs.

Each Child Can Learn

Until now, the educational system seemed to believe that educators are the only ones responsible for the education of

children. Little by little, they have built barriers to keep parents away. As a result, educated parents feel great amounts of frustration and helplessness. They feel obliged to accept the system as it is—without a say in what should be done and as if they were not the ones paying for the education. Less-educated parents miss the opportunity to learn how to guide their children and to motivate them to pursue education as the fun thing to do.

This must change. Parents like us will surely pursue the change at any cost. The best way for children to succeed is to have a coherent, organized effort from parents and educators working together. This is an important element for inclusion because many of the skills for teaching children with special needs can be learned from the extensive experience of the parents.

The question is not whether children with disabilities are smart but rather *how* they are smart. Discovering and helping *all* students learn what they are good at is critical to success. That discovery is far more likely to take place when you challenge them in an inclusive environment. The more they use their natural talents, the more they will succeed and the happier they will be.

When students are in a class that does not call on their strengths, they will be unhappy and restless—"discipline problems" likely to drop out. Children become bored or frustrated when what they can be good at is not recognized.

I will never forget the meeting I had with a so-called Child Study Team. We were supposed to develop an Individualized Educational Plan (IEP) for my son. The learning consultant started by reading a list of what they thought

were the "deficits" our son had. I had come to the meeting with a list of his abilities and strengths. I told them I felt they were not prepared to develop the IEP. Then I got up and left.

Inclusion recognizes and nurtures each student's unique intelligence and ability because a child does better when he or she exercises his strengths. Recognition and respect for what they are good at gives them confidence, which in turn allows them to grow in other areas. In an inclusive environment with cooperative learning, children learn to appreciate their peers' strengths—and they learn from each other.

Everyone can learn. But educators must have high expectations for every student, based on recognized abilities. Children with special needs have a different set of abilities and speed with which they acquire knowledge. Our challenge is to build on what they come with. Only then can *all* children have the opportunity to enter the mainstream of society.

The requirement for America is to give *all* children the chance to experience the powerful adventures of learning, whatever their circumstances may be. In the end there is no mystery to inclusion. It comes down to the extraordinary power an adult can have when he or she pays careful attention to a child.

As parents we have only a few goals for all our kids—that they learn how to learn, communicate, concentrate, get information, feel deeply and act wisely. Always remember that parents are gold; they can transfer the bond they have with their children to the educators and complete the circle for learning success. Join our revolution: respect individuali-

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Carlos Oberti was born in Ecuador. He became a United States citizen in 1990. Mr. Oberti lives in Clementon, New Jersey, with his wife, Jeanne, and their children Rafael, 9, Christopher, 7, Stephanie, 5, and Gabrielle, 3. He works as a marketing manager at MacAndrews and Forbes Company.

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An Administrator's Perspective

Howard P. Blackman



Howard P. Blackman, Ed D., is the Executive Director of the La Grange Area Department of Special Education (LADSE), the consortium of 16 school districts in the west Chicago suburbs. LADSE received Exceptional Parent's 1991 School Mainstreaming Award.

Based on the recent experiences of La Grange Area Department of Special Education (LADSE) school districts and others throughout the United States in expanding inclusion opportunities for students with disabilities, I want to share a series of insights about our recent implementation experiences that parents, educators and our children may find useful.

I am a passionate advocate of inclusion. I believe that many instructional options need to exist not only for students with disabilities, but for all students. Furthermore, I believe that the heterogeneity of the regular class needs to be expanded to help a broader range of learners to experience success—before any thought is given to removing a child with special needs from regular education. Based upon the experiences of our children and families, when educators and families collaborate they can find practical ways to modify regular classrooms, where children with special needs would be if they never met special education placement committees.

I want to encourage others to learn from our district's inclusion experiences as well as their own. Although planning is important, often it not always the very best way to learn about inclusion is to *do* it.

In too many communities and among too many groups with good intentions the debates about inclusion are becoming more and more diverse—with exceedingly toxic results. Instead, I suggest that parents and professionals seek common ground about how to create the best opportunities for children.

Advocacy for maintaining a "full continuum of special education services" is not necessarily an anti-inclusion position. Inclusion advocates also believe in options and the availability of services, which sometimes can mean something other than the regular classroom. People who believe in maintaining a continuum may not necessarily advocate pulling children out of the regular class in order to receive special services.

Concerns about inclusion are frequently rooted in fears about the loss of procedural safeguards. Advocates for inclusion want to ensure that critical procedural safeguards follow each student in all instructional environments.

Many parents and professionals agree that careful implementation of inclusion can be beneficial for a greater num-

ber of students. They also agree that significant issues remain regarding the measurement of outcomes that need to be pursued through careful research.

We need to be guided by the question: "What educational and social experiences will effectively prepare our children to lead fulfilled lives as adults?"

•There is good inclusion and bad inclusion. Good inclusion requires an absolute understanding and administrative commitment to re-allocating resources currently targeted for special education. School systems need to be prepared to spend at least as many resources as are now spent on pullout and/or traditional special education programs by re-allocating these dollars for special education supports within the regular education class.

•Parents and teachers need to develop collaborative partnerships.

While "collaboration" continues to be the buzzword of the '90's and an appropriate goal, its achievement takes much effort, patience and willingness to adapt roles. True collaboration provides new roles. True collaboration provides new roles and validates competence: parent as parent *and* teacher, teacher as teacher *and* learner, learner as learner *and* person—competent about expressing his or her needs, preferences and aspirations. Inclusion requires a rejection of the expert model so pervasive in many schools. We are all competent in contributing talents to facilitate inclusive schools and communities.

•There is nothing wrong with special education. What is being questioned is not the interventions and knowledge that has been acquired through special education training and research. Rather, what is being challenged is the location where these supports are being provided to students with disabilities.

Special education needs to be re-conceptualized as a support to the regular education classroom, rather than as "another place to go." Recent research suggests that what is so wrong about special education is the stigma and isolation that result from being removed from the regular education class for so long. We now have the effective strategies to bring help to the student rather than removing the student from the enriching setting of the regular education class.

•Children, unlike adults, often are positive about inclusion. While adults tend to have anxieties about inclusion (perhaps because it so contradicts our training and assumptions), children without disabilities generally have very positive feelings about helping peers who need assistance.

When asked why adults sometimes assume they may not support each other, children often say, "It's because



adults don't trust us to do the right thing."

Our repeated experiences at LADSE assure us that students of all ages are more likely than not to "do the right thing." Indeed, students are able problem-solvers and contribute to designing new strategies that facilitate successful learning outcomes for their peers with disabilities.

Often we are reminded that the real experts about eight-year-olds' behavior are eight-year-old children. We would do well to rely more on children when we are seeking new strategies to motivate or enhance learning for their peers with challenges.

•Administrators must be committed to listening to teachers. Without administrative commitment to properly supporting students with special needs, "inclusion" would be nothing more than simply dumping. To be done well, inclusion requires commitment at every level to the principle that children with disabilities can learn within the regular classroom given proper supports. It also requires an unswerving commitment by administrators and the school board that resources will be re-allocated to assure appropriate support to the regular education classroom. Ironically, resources usually are readily available. We now better understand the high cost associated with segregated pullout program models, especially those associated with bussing students outside their neighborhood school.

Teachers need to be given absolute, unqualified guarantees that children and teachers will be supported by re-allocating dollars currently spent on sometimes poor service models to better ones with regular education classrooms.

•Parents and professionals must acknowledge the important role special educators play as consultants and team teachers. Regular education teachers need to understand and appreciate the important role of special

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educators if inclusion is to be successful. Again, "place" is the issue. Special educators can work effectively in the regular education classroom with other teachers, thereby enriching educational opportunities for all students.

• Inclusion provides reciprocal benefits for all students. Although the benefits of inclusion for children with disabilities have been emphasized because of the irreplaceable impact that contact with a range of other students provides, we have learned that heterogeneous instructional grouping provides everyone with increased learning opportunities and outcomes.

• Inclusion is a community ideal. Although much of the focus has been in schools—for understandable reasons, do *not* lose sight of the ultimate goal—for each person to find a rightful and meaningful role in the community. There are unlimited resources in the community to help foster inclusion: not just in schools, but in every part of community life. When planning, it may be best to empower community inclusion committees with subcommittees that focus on schools, recreation, transportation, employment, religious organizations, etc. Remember: keep the eye on life after school when inclusion counts the most! Communities, not just schools, need to be prepared to support and be enriched by students with special needs! ■

Since 1980, Howard P. Blackman, Ed D., has served as executive director of LADSE, a special education cooperative nationally recognized for its pioneering school inclusion initiatives. Previously, he served as program director of the Association for Children with Learning Disabilities and as a legislative intern for Syracuse University's Center on Human Policy. Dr. Blackman also served as a presidential appointee to the President's Committee on Mental Retardation.

Editor's Note "Inclusion" as discussed by Carlos Oberti and Howard Blackman is not a reality in many communities. Both authors make clear that true inclusion must include a range of supportive services for children with disabilities as well as for the professional staff involved.

When children with disabilities are merely placed in "regular" classrooms without the special services they may need and/or when teachers are expected to meet all the needs of every child in such a classroom without the assistance of specialists or therapists, it is not inclusion. Nor is it special education or appropriate regular education—it is irresponsible education.

All of us must be prepared to speak out whenever children are "dumped" into regular classrooms without appropriate supports. Sadly, in some communities, some administrators are trying to promote dumping by calling it inclusion.

Future Goals

Application of the Goals 2000: Education America Act to Individuals with Disabilities

The following, which was developed by Senator Tom Harkin (D) of Iowa, is an excerpt of a report submitted to the Senate Committee on Labor and Human Resources in July, 1993.



Introduction

On July 26, 1990, the Americans with Disabilities Act (ADA) was signed into law. The ADA is an omnibus civil rights law that prohibits discrimination on the basis of disability by, among others, entities providing public and private preschool, elementary and secondary education.

The ADA is premised on a system of values that forms the basis of our national disability policy. Under the ADA, disability is recognized as a natural part of the human experience and in no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in all aspects of American society.

In short, the ADA establishes the basis for a national policy that focuses on the inclusion, independence, and empowerment of individuals with disabilities.

The ADA has provided the nation with the impetus to re-examine how it is treating individuals with disabilities in all aspects of American life, including public education. At the same time, we are now in the process of reassessing our educational systems for all students. It is therefore critical to include students with disabilities in our nationwide effort to promote systemic educational reform.

Part B of the Individuals with Disabilities Education Act (IDEA) extends to all students with disabilities the right to a free appropriate public education based on the unique needs of the child. Placement decisions must be based on a child's individualized education program (IEP) in which appropriate services are described. To the maximum extent appropriate, children with disabilities must be educated with children who are not disabled and special classes, separate schooling or other removal of children with disabilities from regular educational environments occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

The promise of part B of IDEA is consistent with the precepts of the ADA. Reports issued by the U.S. Department of Education and others indicate that in certain respects the promises of part B of IDEA have been realized

for many students with disabilities. For example, the number of preschool students receiving a free appropriate public education has increased from 266,000 to 433,000 since 1986.

In far too many other cases, however, the lack of or improper implementation has resulted in little progress. For example, data contained in the Department of Education's "Fourteenth Annual Report to Congress" indicate that little, if any, progress has been made in ensuring that children who can benefit from education in the regular class, with necessary supplementary aids and services, are in fact receiving such an education.

In far too many districts around the country, two separate educational systems have developed with little or no coordination—one system for regular or general education and a separate and distinct system for special education. This isolation and lack of coordination creates artificial barriers to achieving the promises of part B of IDEA, the ADA, and section 504 of the Rehabilitation Act of 1973.

The Committee wishes to send a clear and unequivocal message that the Goals 2000: Educate America Act is fully consistent with the ADA and implements the values and precepts of the ADA in the context of education reform. The Committee also wishes to send the message that this legislation is fully consistent with and complements the spirit and intent of part B of the Individuals with Disabilities Education Act (IDEA) and section 504 of the Rehabilitation Act of 1973.

It is the Committee's expectation that the Goals 2000: Educate America Act will serve as a vehicle for making the promise of part B of IDEA a reality for all students with disabilities. Therefore, under this legislation, students with disabilities, including lesser known and newly emerging disabilities and students with significant and multiple disabilities, must be an integral part of all aspects of education reform, including the application of the National Education Goals and Objectives, the establishment of national and State content, performance and opportunity-to-learn standards and the use of assessments and systems of assessments.

The Committee intends that the exclusion of individuals with disabilities from any aspect of State or local education reform is unacceptable. This means that students with disabilities are entitled to the same high expectations, treatment, and leadership offered to their nondisabled peers, including:

- an expectation that all students across a broad range of performance will be held to high standards if they are to realize their full potential;
- the adoption of flexible teaching strategies and educational planning in order to make the standards meaningful to all students;
- a recognition that leadership from administrators, teachers, related service personnel, and parents is critical;
- a genuine opportunity to participate in a broad and challenging curriculum and to have access to resources sufficient to address other education needs;
- access to social services, health care, nutrition, and child care to remove preventable barriers;

- the adoption of effective strategies that provide effective mechanisms and appropriate paths to the work force as well as to higher education; the appropriate and innovative use of technology; and

- assessments or systems of assessments that are used for a purpose for which they are valid, reliable, fair and free of discrimination (including adaptations and accommodations necessary to permit such participation).

Furthermore, school improvement plans developed by State and local educational agencies and reports prepared by the Secretary of Education, State and local educational agencies, and panels and councils established under this legislation must address the needs of individuals with disabilities and include information and data pertaining to such individuals. In addition, these national and State panels and councils established under this legislation must include representation by and seek the expert guidance of individuals with specialized expertise on the needs and abilities of students with disabilities.

Set out below is a more detailed explanation of how specific provisions of S. 1150 apply to students with disabilities.

• • •

Purpose of the Goals 2000 Act

... Section 102 of the Act sets out the six national education goals: school readiness, school completion, student achievement and citizenship, mathematics and science, adult literacy and lifelong learning, and safe, disciplined, and drug-free schools. The Committee wishes to emphasize that these goals are applicable to all students, including students with disabilities.

With respect to school readiness, the Committee wishes to recognize the great strides that States have made since 1986 in expanding opportunities for children with disabilities aged 3-5 under part B of IDEA. The number of students served has grown from 266,000 to 433,000. In addition the Committee encourages all States to participate in and fully implement the provisions of part H of IDEA, which provides family-centered early intervention services for infants and toddlers with disabilities and their families. Full implementation of these provisions will go a long way toward achieving Goal 1. . . .

With respect to adult literacy and life-long learning, the Committee notes that the National Longitudinal Transition Study funded by the U.S. Department of Education found dramatically low levels of participation among young adults with disabilities in postsecondary education programs (fewer than 17 percent of these youth enter formal postsecondary education programs). The Committee believes that considerable improvement must be made to provide equal access for these young adults.

The Committee also notes that the life-long learning objective is of particular importance to individuals with disabilities. It is the Committee's intent that the provisions in this bill will be construed to be consistent with and further the objectives set out in the recent amendments to part B of

IDEA and title I of the Rehabilitation Act of 1973 relating to transition from school to work and postsecondary education. Youth with disabilities must be meaningfully engaged in school and community-based learning experiences that will assist them in developing competencies to adapt to emerging new technologies, work methods, and training programs.

It also means that teachers and employment specialists should be trained in the unique and diverse competencies as well as learning needs of students with disabilities, with a broad understanding of continually emerging technology, adaptations, and other supports that are necessary for many students to meet with success at work. For example, there is a rich array of technology to support individuals with disabilities on the job. Through supported employment, many individuals who traditionally were unable to enter the competitive workplace are now meeting with a high degree of employment success. . . .

...

National Education Goals Panel

The Committee included authority for the Panel to recommend adjustments to the current goals and objectives in recognition of the fact that there may be a need to clarify the goals, as written, so that they are more responsive to the learning strengths and needs of all students. For example, several of the goals and objectives, as written, may not adequately address the needs of students with severe cognitive impairments. . . .

Under section 203(b) of the Act, the Panel must prepare and submit a national report card. The Committee intends that data presented to parents and the general public include information on the performance of all students, including students with disabilities, and that the report card be submitted in an accessible format. The Committee expects that the report card will separately report data applicable to students with disabilities to the extent separate data is reported for other groups with specific characteristics. . . .

...

National Education Standards and Improvement Council

With respect to the national opportunity-to-learn standards, section 213(c) of the Act specifies that the Council must certify exemplary national standards that will establish a basis for providing all students a fair opportunity to achieve the knowledge and skills described in the voluntary national content standards. Each of these areas are of crucial importance to students with disabilities.

With respect to assessments, section 213(e) of the Act specifies the standards for determining whether to certify an assessment or system of assessments presented on a voluntary basis by a State. . . .

467

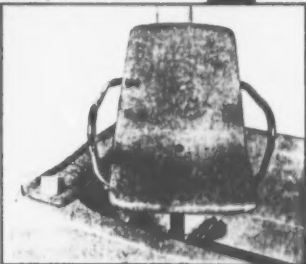
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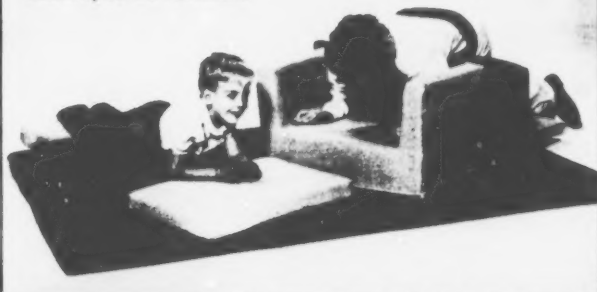
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The certification criteria must address the extent to which an assessment or system of assessments is to be used for a purpose for which it is valid, reliable, fair, and free of discrimination and includes all students, including students with disabilities. . . .

For example, the State of Kentucky has demonstrated that all students with disabilities can be included in a system of assessments. Ninety-eight percent of all students participate in the regular assessment provided to nondisabled students; the remainder participate in alternative portfolio assessment which permits students to demonstrate their educational proficiency through real life activities such as communication with peers, using community supports, maintaining friendships with nondisabled peers and demonstrating actual work experience.

In addition to adaptations, such as those described above, for some students with disabilities who participate in the same assessments as nondisabled students, accommodations may be required, such as: extended time limits, testing a student in a separate room, large print or braille versions of assessments, or use of a reader, scribe, sign language interpreter, or technology. Generally, a student should be provided the same accommodations in assessment that are provided in instruction. For example, if a student learns and performs a task in class with a reader, such accommodation should be provided in assessment.

In sum, the Committee believes it is critical to ensure that all students are part of a State system of assessments and are included in assessment reports. For example, the system of assessments must encourage, not discourage, local educational officials, principals, and teachers to include, not exclude students with disabilities in regular classrooms where such placement is required by part B of IDEA. . . .

...

State and Local Education Systemic Improvement

The Committee understands that many reform efforts carried out by State and local educational agencies have excluded students with disabilities. Such an approach is unacceptable under this legislation.

Section 306 of the Act specifies that any State that desires to receive funding must develop a State improvement plan. The plan must be developed by a broad-based State panel in cooperation with the State educational agency and the Governor. The membership must reflect the diversity of the population with regard to, among other things, disability characteristics. Similar provisions apply to local educational agencies that desire funding.

It is the intent of the committee that the State and local panels be considered a public entity for purposes of the ADA, and thus any plans or proposals made by the panel must be consistent with the prohibition against discrimination on the basis of disability set out in Title II of the ADA and the regulations implementing the ADA. ■

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY

by Marilyn Lash, M.S.W.

Published by Exceptional Parent, in collaboration with the Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center, ©1992 Tufts University.

The following excerpt is from the chapter **What is Special Education?** by Marilyn Lash, M.S.W., and Karin King, M.S.

Glossary of Words used in Special Education

• **Advocate** — A person, often a professional or trained parent, whose primary responsibility is to defend and speak for the best interests of your child.

• **Assessment** — An observation and/or tests designed to determine your child's abilities in specific areas.

• **Due Process** — Each state and local school district has written descriptions of how parents can question and appeal the recommendations, placement and education of their child, and tell who to contact. They describe the rights and responsibilities of the school and parents and give specific steps and timeframes for questions and response by both parents and schools.

• **Educational Objectives** — Accomplishments or tasks set for your child's education. They must be written so that progress can be measured.

• **Evaluation** — A summary of your child's educational needs that includes strengths and weaknesses identified by the assessment.

• **Evaluation Team** — A group of people working together to evaluate and identify your child's educational needs. This team has many names among the

states and is often referred to by their initials. Examples are the P.E.T. for the pupil evaluation team, or P.P.T., for pupil placement team. The abbreviations and names can be very confusing to parents and to "outsiders" such as medical people not usually involved in special education.

You are a very important member of this team. It may also include a teacher, social worker, psychologist, nurse and/or other professionals in education and health care. A team leader or chairperson will be appointed. This person is responsible for co-ordinating all activities of the team and for leading the meetings.

• **Independent Evaluation** — Similar to the evaluation done by the school, but given by a trained person or team employed outside the school system. You may request an independent evaluation at the expense of the school system if you are not satisfied with that done by the school. This independent evaluation must be considered in planning for your child's educational needs.

• **Individualized Education Plan (IEP)** — The plan designed by the evaluation team explaining your child's special needs and how the team plans to meet those needs.

• **Least Restrictive Environment** — Children with disabilities must be educated with able bodied children whenever possible and not separated only because of their disability. Sometimes, however, a separate or specialized

school may be recommended because of the child's individual needs and may give a child more options and services than the public school.

• **Nondiscriminatory Testing and Classification** — The methods used to evaluate your child must be suited to your child's condition. Testing should be done by professionals who understand the nature and unique aspects of your child's injury. For example, a child who writes very slowly because of difficulty holding a pencil due to a muscle or nerve problem in the hands cannot be expected to take a written test in the same time period as a child with total hand use.

• **Referral** — A facility, person or service which may be suggested for your child.

• **Screening** — A brief series of activities designed to find out if a complete evaluation is necessary for your child.

• **Zero Reject** — No child between ages 3 and 21 years can be denied a free and appropriate education because of a disability.



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Parent-Teacher Cooperation: *A Shared Responsibility*

Priscilla Henshaw Presley



Priscilla Henshaw Presley

In 1990, Public Law (P.L.) 101-476, the Individuals with Disabilities Education Act (I.D.E.A.), amended and updated P.L. 94-142 (1975). However, the changes that occurred did not modify one of 94-142's major principles—parent participation. P.L. 94-142 mandated that parents of children with special needs be included in the planning of their child's educational placement and program. This mandate makes parents and educators partners in the educational decisions made and programs developed for children with disabling conditions.

In any partnership, the parties involved must make a special effort to be understanding and cooperative for the relationship to work. Each must be aware of the other's needs and feelings. While both parents and teachers have voiced concerns about how best to work with each other, professionals have had the advantage of research journals and books that relate parents' concerns. Rarely is information that expresses teacher concerns suggestions about how to more effectively make this partnership work made available to parents.

In order to help balance the "information scales," a survey of 56 experienced special education teachers was conducted that asked for teachers' suggestions/concerns. The question asked was: "What could the parents of the children in your room do to make it better/easier for you to talk to them about their child's program, progress or successes?"

The information gathered from the

teachers was combined into the guidelines that follow. They reflect what teachers felt parents could do to help with this important process.

• **Work with the child at home.** It is always helpful to have parents help with homework. Try to follow through on suggestions made for the child. For example, flash cards could be used as extra reinforcement in weak areas. When the child brings home something to do, please make sure he/she does it. If they need help, help them with the work and make sure they get

the paper back to school on time. If the item couldn't get done, send a note. If you cannot instruct your own child at home patiently and effectively, it may be possible to work out an agreement with other parents to work with each other's children.

Encourage your child to bring home completed work to share with you. A positive parent attitude toward school encourages children to have better attitudes and ultimately greater progress. Have a summer folder for your child to work on or summer activities that encourage the use of skills learned during the school year. This helps with carryover during the summer months.

• **Keep the lines of communication open.** Remember that communication is a two-way street. Do ask questions—talk to the teacher. Too many times the professional talks and parents listen. Be more verbal, even if you just say: "I don't understand this. Please explain it again." Be honest with the teacher. If you don't agree, tell the teacher. Don't let such things

"What could the parents of the children in your room do to make it better/easier for you to talk to them about their child's program, progress or successes?"



ride. If something is bothering you, don't hesitate to ask about it. Try to do so in an open, objective manner.

When you attend an IEP meeting, don't hesitate to state your concerns, feelings or suggestions. Your input is important and needed as well as mandated.

If there is something going on outside of school that you feel may be affecting your child—divorce, death, illness, financial problems—by all means contact all of the teachers involved with your child. When children are worried or under stress, their schoolwork and behavior can be affected. Knowing the possible causes of the child's stress can help teachers understand and support the child.

In addition, find out from each teacher the "rules" of the teacher's room, so that you understand the expectations. Ask questions about the educational and behavioral goals for the year—not just the books to be completed, but what specific skills your child is expected to master.

•**Deal with problems.** When there's

a problem concerning teacher-child relationships at school, it is most helpful when a parent can discuss it with the teacher first. If the problem isn't resolved there, then ask for further assistance from the special education supervisor or building principal.

Please don't "bad mouth" or criticize a teacher in front of a child. It encourages poor teacher-child relationships.

•**Be an active participant.** Come to school on parent-teacher conference days and for other meetings. If the teacher is going to come to your home for a home visit, make an effort to be there or arrange for a more convenient time.

Visit your child's classroom to see how he/she spends a typical day. Parents are always welcome.

Respond promptly to letters, especially when conferences have been scheduled. It's better to call and reschedule than to just not show up.

•**Understand the "special" placement.** Expect that your child will have to work just as hard, if not harder, to make progress in a special program. There may be a lot of "territory" to make up cover.

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If your child is in a resource setting, it is important to meet with the special teachers as well as the regular classroom teachers, because the special teachers probably have a greater impact on the child's program. Too frequently, the special teachers are overlooked.

•Understand that teachers are people, too.

It is nice to be appreciated. A simple "thank you" for extra time and effort spent helping your child to accomplish a goal is all that it takes to give a special teacher the motivation to succeed with greater enthusiasm. Teachers need reinforcement, too.

Also, please don't put your child's teacher on a pedestal. As one teacher stated, "...teachers are not perfect. We cannot 'cure' children. We try and work through problems to the best of our knowledge and ability. When that teacher falls off the pedestal you've put them on, it's a long hard fall that may ruin a working relationship

between teacher and parent."

Parents and the professionals that work with them both want what is best for the child. By better understanding each other and communicating wants, needs and feelings, the parent-professional partnership can

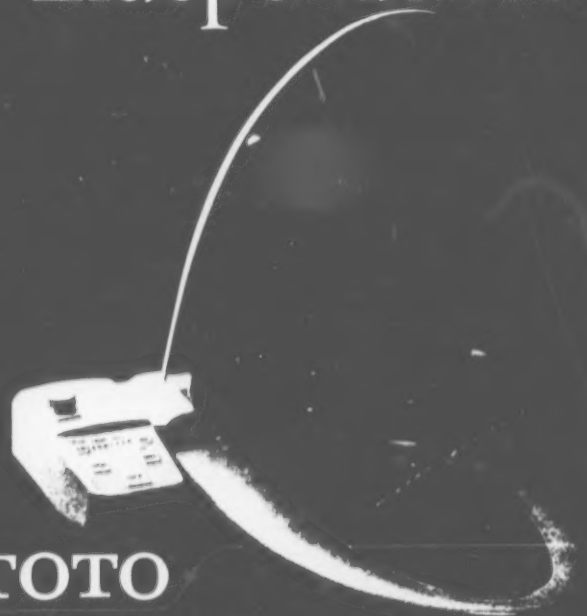
become an unbeatable coalition that ultimately benefits the child. And that is, after all, both the purpose and the intent of I.D.E.A.

In any partnership, the parties involved must make a special effort to be understanding and cooperative for the relationship to work.

Prescilla H. Presley, Ph.D., has served as a member of the faculty in the Department of Special Education

at Southern Illinois University (SIU), Carbondale, for 10 years. Dr. Presley also served as co-director of the Parents Educating Parents Project, whose parent training materials were used in approximately 35 states and 5 foreign countries. She currently serves as director of the Illinois Independent Evaluators Registry Project and will fill the position of center coordinator at SIU's College of Education this fall.

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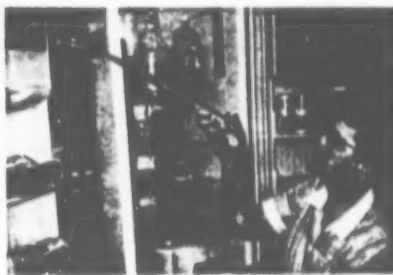
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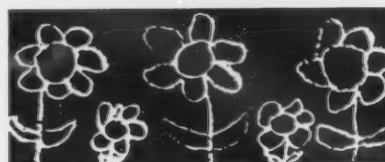
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CROTCHED MOUNTAIN REHABILITATION CENTER, INC.

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1 VERNEY DRIVE, GREENFIELD, NEW HAMPSHIRE 03047 (603) 547-3311



Agape Village

helps develop happy, fulfilled people by
promoting self-worth and self-sufficiency.

Agape Village, a residential community for mentally retarded/intellectually disabled adults, provides a learning atmosphere in which a highly qualified professional staff offer Villagers opportunities for success in

- learning home living skills and money management
- vocational and job training
- social/emotional growth
- physical fitness and recreation
- spiritual growth and church participation

Contact: Glenda B. Wallace, Ph.D., Agape Village
3711 Agape Village Rd., Macon, GA 31210, 912-471-3700

No Behavior Problem is TOO TOUGH

for Behavior Research Institute, a 24 hour, 365 day program which serves persons with autism, mental retardation, or emotional disorders.

- No psychotropic drugs
- Zero rejections and zero expulsions
- Consistent behavior modification
- One computer for each student
- Open visiting policy

We also operate Hope Academy, a separate program for adolescents with average to high IQs who exhibit problem behaviors such as fire-setting, running away, refusing to cooperate, drug abuse, and inappropriate sexual conduct.

Our friends and relatives who see him after not having seen him for several years are astounded by the remarkable improvement he has made during his years at BRI.

Paul Peterson, Ph.D., parent

Behavior Research Institute

240 Laban Street, Providence, RI 02909 1-800-231-5405

National Organizations for Specific Disabilities and Conditions

These national groups offer needed services, resources and support to parents and professionals. Services provided may include rehabilitation, housing, advocacy, information networking and more.

Acoustic Neuroma

Acoustic Neuroma Association
P.O. Box 12402
Atlanta, GA 30355
(404) 237-8023, (404) 237-2704 (FAX)

Agensis of the Corpus Callosum

ACC Network
86 N. Main St.
Orono, ME 04473
(207) 866-2062

Aicardi Syndrome

Aicardi Syndrome Awareness and Support Group
29 Delavan Ave.
Toronto, Ontario, Canada, M5P 1T2
(416) 481-4095

Aicardi Syndrome Newsletter, Inc.
5115 Troy Urbana Rd.
Cassstown, OH 45312
(513) 339-6033 (phone/FAX)

Albinism and Hypopigmentation

National Organization for Albinism and Hypopigmentation (NOAH)
1500 Locust St., Suite 1816
Philadelphia, PA 19102
(800) 473-2310, (215) 545-2322

Amputation

National Amputation Foundation
73 Church St.
Malverne, NY 11565
(516) 887-3600, (516) 887-3667

Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease)

Amyotrophic Lateral Sclerosis Association
21021 Ventura Blvd., Suite 321
Woodland Hills, CA 91364
(800) 782-4747

Angelman Syndrome

Angelman Syndrome Foundation
5950-77 SW 20th Ave.
Gainesville, FL 32607
(904) 332-3303 (phone/FAX)

Anorectal Malformations

Pull-thru Network
1 Circle Rd.
Darien, CT 06820
(203) 655-6288

Aphasia (inability to form words)

National Aphasia Association
Young People's Network
P.O. Box 1887

Murray Hill Station
New York, NY 10156-0611
(800) 922-4622

Arnold-Chiari Syndrome

Arnold-Chiari Family Network
67 Spring Street
Weymouth, MA 02188
(617) 337-2366

Arthritis

American Juvenile Arthritis Organization
1314 Spring St. NW
Atlanta, GA 30309
(404) 872-7100, (404) 872-0457 (FAX)

Arthrogyrosis

Avenues
National Support Group for Arthrogyrosis Multiplex Congenita
P.O. Box 5192
Sonoma, CA 95370
(209) 928-3688

Asthma and Allergy

Asthma and Allergy Foundation of America
1125 15th St. NW, Suite 502
Washington, DC 20005
(800) 7AS-THMA
(202) 466-8940 (FAX)

Ataxia (loss of coordinated movement)

National Ataxia Foundation
750 Twelve Oaks Center
15500 Wayzata Blvd.
Wayzata, MN 55391
(612) 473-7666, (612) 473-9289 (FAX)

Attention Deficit Disorder

National Attention Deficit Disorder Assn. (NADDA)
(local support groups)
19262 Jamboree Road
Irvine, CA 92715
(membership in NADDA)
P.O. Box 488
West Newbury, MA 01985
(800) 487-2282

Children with Attention Deficit Disorders (C.H.A.D.D.)

499 N.W. 70th Ave., Suite 308
Plantation, FL 33317
(305) 587-3700, (305) 587-4599 (FAX)

Autism

Autism Network International (ANI)
P.O. Box 1545
Lawrence, KS 66044

Autism Society of America
7910 Woodmont Ave., Suite 650
Bethesda, MD 20814
(800) 3AU-TISM, (301) 657-0881
(301) 657-0869 (FAX)

National Autism Hotline/Autism Services Center
605 Ninth St.
Prichard Building
P.O. Box 507
Huntington, WV 25710-0507
(304) 525-8014, (304) 525-8026 (FAX)

Families of More Able Autistic People (MAAP)
P.O. Box 524
Crown Point, IN 46307

Batten's Disease

Batten's Disease Support and Research Association
2600 Parsons Avenue
Columbus, OH 43207
(800) 448-4570

Beckwith-Wiedemann Syndrome

Beckwith-Wiedemann Support Network
3206 Braeburn Circle
Ann Arbor, MI 48108
(313) 973-0263, (313) 973-9721 (FAX)

Birth Defects

Association of Birth Defect Children
Orlando Executive Park
5400 Diplomat Circle, Suite 270
Orlando, FL 32810
(407) 629-1466 (phone/FAX)

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave.
White Plains, NY 10605
(914) 428-7100, (914) 428-8203 (FAX)

National Birth Defects Center
30 Warren Street
Boston, MA 02135
(617) 787-5958, (617) 787-9019 (FAX)

National Network to Prevent Birth Defects
Box 15309 SE Station
Washington, DC 20003
(202) 543-5450

Brain Damage

Andrew Blake Foundation
Box 67A9, Row 1
Winona, MN 55987
(507) 452-5734

Brain Diseases and Disorders (general)

Children's Brain Diseases Foundation
350 Parnassus Ave., Suite 900
San Francisco, CA 94117
(415) 565-6259, (415) 863-3452 (FAX)

Fighters for Encephaly Defects Support (FEDS)
3032 Brereton Ct.
Pittsburgh, PA 15219
(412) 687-6437

Brain Tumor

American Brain Tumor Association
720 River Rd., Suite 146
Des Plaines, IL 60018
(708) 827-9910
(800) 886-2282 (patient line)
(708) 827-9918 (FAX)

Cancer

American Cancer Society
1599 Clifton Rd. NE
Atlanta, GA 30329-4251
(800) ACS-2345

AMC Cancer Information Center
1600 Pierce St.
Lakewood, CO 80214
(800) 525-3777

Candlelighters Childhood Cancer Foundation
7910 Woodmont Ave., Suite 460
Bethesda, MD 20814
(800) 366-2223, (301) 718-2686 (FAX)

National Cancer Institute
Cancer Info. Resource Branch
9000 Rockville Pike
Bldg. 31, Room 10A-16
Bethesda, MD 20892
(800) 4-CANCER

Familial Polyposis Registry
Mount Sinai Hospital
500 University Ave., Suite 1157
Toronto, ON Canada M5G 1X5
(416) 586-8334

G.I. Polyposis and Hereditary Colon Cancer Registry
Ctr for Medical Genetics,
Johns Hopkins Hospital,
600 N. Wolfe St.
Baltimore, MD 21287-4922
(410) 955-3875

Intestinal Multiple Polyposis and Colorectal Cancer (IMPACC)
1008-101 Brnker Drive
Hagerstown, MD 21740
(301) 791-7526

Corporate Angel Network (CAN)
Westchester County Airport
Building 1
White Plains, NY 10604
(914) 328-1313, (914) 328-3938 (FAX)

Cardio-Facio-Cutaneous Syndrome

CFC Support Network
157 Alder Ave.
McKee City, NJ 08232
(609) 646-5606

Cerebral Palsy

United Cerebral Palsy Association
1522 K Street NW, #1112
Washington, D.C. 20005
(800) 872-5827, (202) 842-1266
(202) 842-3519 (FAX)

Charcot-Marie-Tooth Disease

Charcot-Marie-Tooth (CMT) International
1 Springbank Drive
St. Catharines, ON, Canada L2S 2K1
(416) 687-3630



National Organizations for Specific Disabilities and Conditions

Charcot-Marie-Tooth Association
Crozer Mills Enterprise Center
601 Upland Ave., Upland, PA 19015
(215) 499-7486, (215) 489-7429 (FAX)

CHARGE Syndrome •

CHARGE Syndrome Foundation, Inc.
Coloboma of the eye
Heart malformations
Atresia of the Choanae (nasal)
Retardation of growth and/or development
Genital Hypoplasia
Ear anomalies
2004 Parkade Blvd
Columbia, MO 65202
(314) 442-7604

Children who have Died

Compassionate Friends
P.O. Box 3696
Oak Brook, IL 60522-3696
(708) 990-0010, (708) 990-0246 (FAX)

A.M.E.N.D. (Aiding Mothers & Fathers Experiencing Neonatal Death)
4324 Berrywick Terrace
St. Louis, MO 63128
(314) 487-7582

Chromosome 9p-

Support Group for 9p-
675 N. Round Table Drive
Las Vegas, NV 89110
(702) 453-0788

Support Group for Monosomy 9p
43304 Kipton Nickle Plate Road
La Grange, OH 44050
(216) 775-4255

Trisomy 9 International Parent Support (TIPS)
Children's Hospital of Michigan
3901 Beaubien Blvd.
Detroit, MI 48201-2196
(313) 745-4513

Chromosomes 18 and 13

Chromosome 18 Registry & Research Society
6302 Fox Head
San Antonio, TX 78247
(512) 657-4968 (phone/FAX)

Support Organization for Trisomy 18, 13 and Related Disorders
2982 S. Union St.
Rochester, NY 14624
(716) 594-4621

Chromosome Deletion

Chromosome Deletion Outreach
P.O. Box 532
Center Monches, NY 11934
(516) 878-3510

Chronic Dizziness and Balance Disorders

Pen Pal Support Group for Chronic Dizziness & Balance Disorders
Box 305
Elliot, IA 51532
(712) 767-2325

Chronic Illness

Parents of Chronically Ill Children
1527 Maryland St.
Springfield, IL 62702
(217) 522-6810

Families of Children Under Stress (FOCUS)
P.O. Box 1058
Conyers, GA 30207
(404) 483-9845

Cleft Palate

Cleft Palate Foundation
1218 Grandview Ave
Pittsburgh, PA 15211
(800) 24-CLEFT, (412) 481-1376
(412) 481-0847 (FAX)

Prescription Parents, Inc.
P.O. Box 161
W. Roxbury, MA 02132
(617) 527-0878

Cockayne Syndrome

Share and Care
1294 S Street
North Valley Stream, NY 11580
(516) 825-2284

Coffin-Lowry Syndrome

Coffin-Lowry Syndrome Foundation
6790 N.E. Day Road W
Bainbridge Island, WA 98110
(206) 842-1523

Cooley's Anemia

Cooley's Anemia Foundation
105 East 22nd Street, Suite 911
New York, NY 10010
(212) 598-0911, (212) 598-4892 (FAX)

Cornelia de Lange Syndrome

Cornelia de Lange Syndrome Foundation
60 Dyer Avenue
Collinsville, CT 06022-1201
(800) 223-8355, (800) 753-CDLS
(203) 693-0159, (203) 693-6819 (FAX)

Craniofacial Disorders

AboutFace U.S.A.
1002 Liberty Ln.
Warrington, PA 18976
(800) 225-FACE
(215) 491-0603 (FAX)

AboutFace
99 Crowns Lane, 3rd Floor
Toronto, ON Canada M5R 3P4
(416) 944-FACE
(416) 944-2488 (FAX)

FACE of Sarasota, Inc.
Bernice Brooks Bergen, exec. dir.
P.O. Box 1424
Sarasota, FL 34230
(813) 955-9250, (813) 925-2929 (FAX)

Children's Craniofacial Association
10210 N. Central Expressway
Suite 230, LB37
Dallas, TX 75231
(800) 535-3643, (214) 368-3590
(214) 368-3599 (FAX)

Let's Face It
P.O. Box 711
Concord, MA 01742
(508) 371-3186

The New England Center for Autism is dedicated to providing the most caring, comprehensive, and innovative education

available today to children with autism and mental retardation.

Our behaviorally oriented, community-based center, serving students aged 3 to adult, has revolutionized the way in which children with autism and developmental disabilities are cared for and educated. At admission, these students have severe behavioral problems including aggression, self-injurious behavior and hyperactivity. Half of our students have seizure disorders.

Our educational facility is located in

Southboro, Massachusetts, with 12 attractive student homes in nearby neighborhoods. Our professional staff includes clinical psychologists, special educators, social workers, nurses and physicians. Appropriate students are welcomed from all over the U.S.

For more information, please contact
Vincent Strully, Jr., Executive Director.

33 Turnpike Road • Southboro, MA 01772 • (508) 481-1015 • Just 20 miles west of Boston

Children of Promise



"I want to thank
The Center's staff for
the foresight, persistence
and expertise in executing
perhaps the finest program
for autistic children and
adults in the nation."

Barbara C. Fries,
parent

The
**New England
Center for
Autism, Inc.**

FACES—National Association for the Craniofacially Handicapped
P.O. Box 11082
Chattanooga, TN 37401
(800) 332-2373, (615) 267-3124 (FAX)

National Foundation for Facial Reconstruction

317 East 34th Street, 9th Floor
New York, NY 10016
(800) 422-FACE, (212) 263-6656
(212) 263-7534 (FAX)

Hemifacial Microsomia/Goldenhar Syndrome

Family Support Network
84 Gleniffer Hill Rd.
Richboro, PA 18954
(215) 364-3199

Cri Du Chat (Cat Cry) Syndrome

The 5p- Society
11609 Oakmont
Overland Park, KS 66210
(913) 469-8900

Crohn's Disease and Ulcerative Colitis

Crohn's & Colitis Foundation of America
444 Park Ave. S., 11th Floor
New York, NY 10018
(800) 343-3637, (212) 779-4098 (FAX)

Cushing Syndrome

National Cushing Syndrome Association
4645 Van Nuys Blvd., Suite 104
Sherman Oaks, CA 91403
(818) 788-9239, (818) 788-2413 (FAX)

Cyclic Vomiting Syndrome

Cyclic Vomiting Syndrome Association
13180 Caroline Court
Elm Grove, WI 53122
(414) 784-6842, (414) 821-5494 (FAX)

Cystic Fibrosis

Cystic Fibrosis Foundation
6931 Arlington Rd.
Bethesda, MD 20814
(800) FIG-HTCF, (301) 951-4422,
(301) 951-6378 (FAX)

Cystinosis

Cystinosis Foundation
1212 Broadway, Suite 830
Oakland, CA 94612
(800) 392-8458

Cytochrome C Oxidase Deficiency

Cytochrome C Oxidase Deficiency Parental Research and Support Foundation
109 Major St.
Aliquippa, PA 15001
(412) 375-8347

Diabetes

American Diabetes Association
National Service Center
1660 Duke St.
Alexandria, VA 22314
(800) 232-3472, (703) 549-1500
(703) 683-2890 (FAX)

Canadian Diabetes Association
15 Toronto St., Suite 1001
Toronto, ON Canada M5C 2E3
(416) 363-3373, (416) 363-3393 (FAX)

Juvenile Diabetes Foundation International
432 Park Ave. S., 16th Floor
New York, NY 10016
(800) 533-2873, (212) 889-7575
(212) 532-8791 (FAX)

DiGeorge Syndrome

Information and Support for DiGeorge Syndrome Families
4075-B Miramar St.
La Jolla, CA 92037
(619) 453-8340

Down Syndrome

Association for Children with Down Syndrome
2616 Martin Ave.
Bellmore, NY 11710
(516) 221-4700, (516) 221-4311 (FAX)

Canadian Down Syndrome Society
12837 76th Ave., Suite 206
Surrey, BC, Canada V3W 2V3
(604) 599-6009, (604) 599-6165 (FAX)

Caring Inc.
P.O. Box 400
Milton, WA 98354
(206) 922-8607

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
(800) 232-6372, (404) 633-1555
(404) 633-2817 (FAX)

National Down Syndrome Society
666 Broadway, Suite 810
New York, NY 10012
(800) 221-4602, (212) 460-9330
(212) 979-2873 (FAX)

Dysautonomia Foundation

Dysautonomia Foundation
20 E. 46th Street, Rm. 302
New York, NY 10017
(212) 949-6644, (212) 682-7625 (FAX)

Dyslexia

Dyslexia Research Institute, Inc.
4745 Centerville Road
Tallahassee, FL 32308
(904) 893-2216, (904) 893-2440 (FAX)

The Orton Dyslexia Society

8600 La Salle Rd.
Chester Bldg., Suite 382
Baltimore, MD 21286-2044
(800) 222-3123, (410) 296-0232
(410) 321-5069 (FAX)

Dystonia

Dystonia Medical Research Foundation
1177 W. Hastings St., Suite 2000
Vancouver, BC Canada V6Z 2K6
(604) 661-4886

Dystonia Medical Research Foundation
One East Wacker Drive, Suite 2900
Chicago, IL 60601-2001
(312) 755-0198, (312) 321-5710 (FAX)

Did I Hear You Say Help?



National Christian Resource Center on Mental Retardation
a service of:
Bethesda
LUTHERAN HOMES AND SERVICES, INC.
700 Hoffman Dr.
Watertown, WI 53094
A.L. Napolitano
Executive Director
Call 1-800-369-INFO

- ☐ Are you looking for appropriate services for yourself, your family member or client?
- ☐ Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

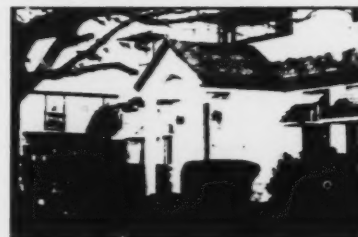
Then call our toll-free hotline 1-800-369-INFO.

We offer:

- Lists of services in specified geographic areas.
- Referrals to advocacy and support groups.
- Referrals to religious education programs.
- Lists of religious materials.

Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

Crystal Springs School



Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- Approved by the Massachusetts Department of Education as a special education resource.
- Licensed by the Massachusetts Office for Children.
- Serving severely and profoundly multiply handicapped children and young adults aged 3-22.
- 60 acre campus in Southeast Massachusetts, close to Boston, Cape Cod, Providence and Newport, R.I.

For information, Please Call:
Cheryl Andrade, Admissions Coordinator
(508) 644-5537

Ectodermal Dysplasia

National Foundation for Ectodermal Dysplasia
219 E. Main
P.O. Box 114
Mascoutah, IL 62258-0114
(618) 566-2020, (618) 566-4718 (FAX)

Ehlers-Danlos Syndrome

Ehlers-Danlos National Foundation
P.O. Box 1212
Southgate, MI 48195
(313) 282-0180, (313) 282-2793 (FAX)

Eosinophilic Myalgia Syndrome

Eosinophilic Myalgia Syndrome Support Group
c/o T.V. Workshop
3637 Green Rd.
Beechwood, OH 44122

Epilepsy

Epilepsy Foundation of America (EFA)
4351 Garden City Drive
Landover, MD 20785-2267
(800) EFA-1000, (301) 459-3700
(301) 577-4941 (FAX)

Evans Syndrome

Evans Syndrome Support and Research Group
5630 Devon St.
Port Orange, FL 32127
(904) 760-3031, (904) 761-6008 (FAX)

Extracorporeal Membrane Oxygenation

ECMO Moms and Dads International Parent Support
P.O. Box 53848
Lubbock, TX 79453
(806) 889-3877, (806) 745-8130

Fanconi Anemia

Canadian Fanconi Anemia Research Fund
85 Ormond Drive
Oshawa, ON, Canada L1G 6T3

Fanconi Anemia Support Group
66 Club Road, Suite 390
Eugene, OR 97401
(503) 687-4658, (503) 484-0892 (FAX)

Fibular Hemimelia

Superkids Newsletter
60 Clyde St.
Newton, MA 02160

Fragile X Syndrome

National Fragile X Foundation
1441 York St., Suite 215
Denver, CO 80206
(800) 688-8765, (303) 333-6155
(303) 333-4369 (FAX)

Freeman-Sheldon Syndrome

Freeman-Sheldon Parent Support Group
509 E. Northmont Way
Salt Lake City, UT 84103
(801) 364-7060

Galactosemia

Parents of Galactosemic Children
20981 Solano Way
Boca Raton, FL 33433
(407) 852-0266

Gaucher Disease

National Gaucher Foundation
19241 Montgomery Village Ave., E-21
Gaithersburg, MD 20879
(800) 925-8885, (301) 990-4898 (FAX)

Genetic Conditions (general)

Alliance of Genetic Support Groups
35 Wisconsin Cr. #440
Chevy Chase, MD 20815-7015
(800) 336-GENE, (301) 652-5553
(301) 654-0171 (FAX)

National Foundation for Jewish Genetic Diseases
250 Park Avenue, Suite 1000
New York, NY 10017
(212) 371-1030

Hereditary Disease Foundation
1427 7th Street, Suite 2
Santa Monica, CA 90401
(310) 458-4183, (310) 458-3937 (FAX)

Glycogen Storage Disease

Association for Glycogen Storage Disease
P.O. Box 896
Durant, IA 52747
(319) 785-6038 (phone/FAX)

Group B Strep

Group B Strep Association
P.O. Box 16515
Chapel Hill, NC 27516
(919) 932-5344

Growth Disorders (general)

Human Growth Foundation
7777 Leesburg Pike
Falls Church, VA 22043
(800) 451-6434, (703) 883-1773
(703) 883-1776 (FAX)

Guillain-Barré Syndrome

Guillain-Barré Syndrome Foundation International
P.O. Box 262
Wynnewood, PA 19096
(215) 667-0131, (215) 667-7036 (FAX)

Hallerman-Streiff Syndrome

Hallerman-Streiff Support Group
1367 Beulah Park Drive
Lexington, KY 40517
(606) 273-6928

Head Injuries

National Head Injury Foundation
1776 Massachusetts Avenue, NW,
Suite 100
Washington, DC 20036-1904
(202) 296-6443
(800) 444-6443 (helpline)
(202) 296-8850 (FAX)

Anyone who has ever visited the Cardinal Cushing School and Training Center and Braintree St. Coletta Day School will no doubt express that the experience was inspirational. The two programs, operated by St. Coletta's of Massachusetts, are reminders that miracles can happen when exceptional children are not treated as mentally disabled.

Established in 1947, St. Coletta's has blossomed into two distinct schools with over 200 staff members. The philosophy of the organization is to provide an environment where developmentally-delayed children can develop their abilities in an atmosphere of confidence and joy. Today, the schools offer what may be the best educational programs available to exceptional children, consistently producing amazing results.

At the Braintree St. Coletta Day School, approximately 70 students ages 5-22, enjoy a staff ratio of 1-3 which enables instructors to provide a high degree of personal interaction. From occupational education and behavioral management - to the development of social and domestic skills - activities enable students to gain the highest possible degree of independence. A residential component is also available.

Exceptional Schools

Braintree St. Coletta Day School
Cardinal Cushing School and Training Center



John W. Shyne, Jr., President
(617) 826-6371
Hanover, MA

Located in Hanover, the Cardinal Cushing School and Training Center provides roughly 160 students with academic, vocational, and residential programs for all levels of developmentally-delayed children and young adults ages 6-22. With residential placement for 130 students - accommodating 30 day attendees - the programs guide students to a chosen career by instilling in them the academic, functional and social skills.

From culinary arts and hotel maintenance, horticulture, maintenance and more, students receive hands-on training. In addition, programs in theater and sporting, as well as the benefits of living alongside peers, further increase social development. After leaving the school, most students are able to find employment. In fact, a notable alumni is Chris Burke, star of the ABC TV series "Life Goes On," introduced to performing arts through the school.

• • Services Include • •

Prader-Willi Program
Vocational Training
Independent Living Training
Adaptive Physical Therapy
Speech Therapy • Counseling
Community Skills • Summer Programs
Bi-Lingual (Spanish) Program

Hearing Impairments

HEAR Now

4001 S. Magnolia Way, Suite 100
Denver, CO 80237
(800) 648-HEAR (Voice/TDD)
(800) 648-HEAR

National Captioning Institute

5203 Leesburg Pike
Falls Church, VA 22041
(800) 533-WORD
(800) 321-TDDS (TDD)
(703) 998-2400 (voice/TDD)
(703) 998-2458 (FAX)

Alexander Graham Bell Association for the Deaf

3417 Volta Place NW
Washington, DC 20007-2778
(202) 337-5220 (voice/TTY)

American Society for Deaf Children (ASDC)

814 Thayer Avenue
Silver Spring, MD 20910
(800) 942-ASDC

Auditory-Verbal International, Inc.

6 South Third St., Suite 305
Easton, PA 18042
(215) 253-6616, (215) 253-4434 (TDD)
(215) 253-6709 (FAX)

Better Hearing Institute

P.O. Box 1840
Washington, DC 20013
(800) EAR-WELL (voice/TDD)
(703) 750-9302 (FAX)

Canadian Hearing Society

271 Spadina Road
Toronto, ON Canada M5R 2V3
(416) 964-9595, (416) 964-0023 (TDD)
(416) 964-2066 (FAX)

International Organization for the Education of the Hearing-Impaired

3417 Volta Place NW
Washington, DC 20007
(202) 337-5220 (Voice/TDD)

John Tracy Clinic

806 W. Adams Blvd.
Los Angeles, CA 90007
(800) 522-4582 (voice/TDD)
(213) 748-5481, (213) 747-2924 (TTY)
(213) 749-1651 (FAX)

LISTEN, Inc.

P.O. Box 27213
Tempe, AZ 85285
(602) 921-3886

National Association for the Deaf (NAD)

814 Thayer Ave.
Silver Spring, MD 20910-4500
(301) 587-1788, (301) 587-1789 (TDD)
(301) 587-1791 (FAX)

National Cued Speech Association

P.O. Box 31345
Raleigh, NC 27622
(919) 828-1218 (voice/TDD)
(919) 828-1862 (FAX)

International Hearing Society

20361 Middlebelt Rd.
Livonia, MI 48152
(800) 521-5247, (313) 478-2610
(313) 478-4520 (FAX)

National Information Center on Deafness

Gallaudet University
800 Florida Ave. NE
Washington, DC 20002-3695
(202) 651-5051, (202) 651-5052 (TDD)
(202) 651-5054 (FAX)

National Technical Institute for the Deaf

Rochester Institute of Technology
Lyndon Baines Johnson Building
52 Lomb Memorial Drive
Rochester, NY 14623-5604
(716) 475-6400, (716) 475-6500 (FAX)

Self Help for Hard of Hearing People, Inc. (SHHH)

7800 Wisconsin Ave.
Bethesda, MD 20814
(301) 657-2248, (301) 657-2249 (TDD)
(301) 913-9413 (FAX)

Signing Exact English (SEE) Center for the Advancement of Deaf Children

P.O. Box 1181
Los Alamitos, CA 90720
(310) 430-1467, (310) 795-6614 (FAX)

TRIPOD GRAPEVINE

2901 N. Keystone St.
Burbank, CA 91504
(800) 352-8888 (voice/TDD)
(818) 972-2090 (FAX)

VOICE for Hearing-Impaired Children

124 Eglinton Avenue W, Suite 420
Toronto, ON Canada M4R 2G8
(416) 487-7719, (416) 487-7423 (FAX)

Deafpride, Inc.

1350 Potomac Ave. SE
Washington, DC 20003
(202) 675-6700 (voice/TDD)
(202) 547-0547 (FAX)

Captioned Films & Videos for the Deaf

Modern Talking Picture Services
5000 Park Street N
St. Petersburg, FL 33709
(800) 237-6213, (813) 541-7571
(813) 545-8782 (FAX)

Deaf-REACH

3521 12th Street NE
Washington, DC 20017
(202) 832-6681, (202) 832-8454 (FAX)

Heart Disorders

American Heart Association

7272 Greenville Ave.
Dallas, TX 75231-4596
(214) 373-6300, (214) 706-1341 (FAX)

Heart, Lung and Blood Disorders

National Heart, Lung and Blood Institute

P.O. Box 105
Bethesda, MD 20824-0105
(301) 251-1222

Hemochromatosis

Hemochromatosis Foundation

P.O. Box 8569
Albany, NY 12208
(518) 489-0972

Hemophilia

Canadian Hemophilia Society

1450 City Councillors, Ste. 840
Montreal, PQ Canada H3A 2E6
(514) 848-0503, (515) 848-9661 (FAX)

National Hemophilia Foundation (NHF)

110 Greene St., Rm. 303
New York, NY 10012
(212) 219-8180, (212) 966-9247 (FAX)



The Developmental School

380 Washington Avenue
Roosevelt, NY 11575

Serving Children with Cerebral Palsy and a wide range of other Mild to Severe Disabilities

On Site: Speech, Physical & Occupational Therapy, Adapted Toy Lending Library, Communicational Laboratory, Computer Training, Recreational Programs, Family Support Services, A N.Y.S. Approved Evaluation Facility, Extensive Medical, Dental and Audiology Services.

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Fax (516) 378-3791**

487

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.



EVERGREEN CENTER

345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597



Superior Quality Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day and residential programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources. Few other programs can offer such an open and productive relationship.

There are five programs for women (from semi-independent to supportive) including one specifically designed for mature women. **A new community-based program for semi-independent men has been added.** Located in a modern, attractive home, the program offers training in home care and maintenance, budgeting, household management, and participation in an established vocational program.

All Programs Offer These Advantages

- Life skills and vocational training.
- Employment opportunities at Martha Lloyd and in the Troy community.
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation.
- A caring professional staff experienced in working with developmental disabilities.
- Our interdisciplinary team approach assures continuity and consistency in individual planning.
- Unique leisure and recreational experiences in a rural community setting.
- Excellent health care provided by on-staff health professionals and a community medical center.
- Annual fees among the lowest in the nation.



**MARTHA
LLOYD
COMMUNITY
SERVICES**

**For Information Call
(717) 297-2185**

or write Martha Lloyd Community Services
190 West Main St., Troy, PA 16947

483

Histiocytosis

Histiocytosis Association of America

609 New York Rd.
Glassboro, NJ 08028
(800) 548-2758, (609) 881-4911
(609) 589-6614 (FAX)

ask about their computer bulletin board service

Huntington's Disease

Huntington's Disease Society of America

140 W. 22nd Street, 6th Fl.
New York, NY 10011-2420
(212) 242-1968, (212) 243-2443 (FAX)

Hydrocephalus

Hydrocephalus Association

870 Market Street, Suite 955
San Francisco, CA 94102
(415) 776-4713

National Hydrocephalus Foundation

400 N. Michigan Ave., Suite 1102
Chicago, IL 60611-4102
(815) 467-6548

Hydrocephalus Support Group

P.O. Box 4236
Chesterfield, MO 63006
(314) 532-8228

Guardians of Hydrocephalus Research Foundation

2618 Avenue Z
Brooklyn, NY 11235
(800) 458-8655, (718) 743-4473
(718) 743-1171 (FAX)

Immune Deficiency

Immune Deficiency Foundation (IDF)

P.O. Box 586
Columbia, MD 21045
(301) 730-8837

Incontinence

Help for Incontinent People

P.O. Box 544
Union, SC 29379
(803) 579-7900, (803) 579-7902 (FAX)

Simon Foundation for Continence

P.O. Box 815
Wilmette, IL 60091
(800) 23-SIMON
(708) 864-9758 (FAX)

Intestinal Pseudo-Obstruction

American Pseudo-Obstruction and Hirschsprung Disease Society, Inc.

P.O. Box 772
Medford, MA 02155
(617) 395-4255, (617) 396-6868 (FAX)

Intraventricular Hemorrhage

I.V.H. Parents

P.O. Box 56-1111
Miami, FL 33256-1111
(305) 232-0381, (305) 232-9890 (FAX)

Joubert Syndrome

Joubert Syndrome Parents-in-Touch Network

12348 Summer Meadow Road
Rock, MI 49880
(906) 359-4707

Kidney Disorders

Polycystic Kidney Research Foundation (PKR)

922 Walnut St., Suite 411
Kansas City, MO 64106
(800) 444-8197
(800) PKD-CURE
(816) 421-1869, (816) 421-7208 (FAX)

American Kidney Fund

6110 Executive Blvd., Suite 1010
Rockville, MD 20852
(800) 638-8299
(301) 881-0898 (FAX)

National Kidney Foundation

30 East 33rd Street, 11th Floor
New York, NY 10016
(800) 622-9010, (212) 889-2210

Klippel-Trenaunay Syndrome

Klippel-Trenaunay Support Group

4610 Wooddale Ave.
Edina, MN 55424
(612) 925-2596

Lactic-Acidosis

Lactic-Acidosis Support Group

P.O. Box 480282
Denver, CO 80248-0282
(303) 287-4953

Landau-Kleffner Syndrome

C.A.N.D.I.E. Support Group

4414 McCampbell Drive
Montgomery, AL 36106
(205) 271-3947 (phone/FAX)

Laurence-Moon-Bardet-Biedl Syndrome

Laurence-Moon-Bardet-Biedl Syndrome Network

18 Strawberry Hill
Windsor, CT 06095
(203) 688-7880

Learning Disabilities

Learning Disabilities Association of America

4156 Library Rd.
Pittsburgh, PA 15234
(412) 341-1515, 341-8077
(412) 344-0224 (FAX)

Learning Disabilities Association of Canada

323 Chapel St., Suite 200
Ottawa, ON Canada K1N 7Z2
(613) 238-5721, (613) 235-5391 (FAX)

National Center for Learning Disabilities

381 Park Ave. S, Suite 1420
New York, NY 10016
(212) 545-7510
(212) 545-9665 (FAX)

Home Away From Home

Quality care in a state-of-the-art medically oriented, yet home-like, facility for chronically ill infants, children, and young adults. A one of a kind program staffed by doctors, nurses, therapists, and teachers. If you are thinking about having your loved one cared for outside your home, consider Hacienda de los Angeles with 26 years of experience helping families and their chronically ill family members. Hacienda is located in a semi-rural setting bordered by beautiful South Mountain Park, yet is less than five minutes from the Owens Medical Center.

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- Physician services and round-the-clock nursing care.
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- In-house physical, occupational, and speech therapy.
- Nutritional services by a certified nutritionist.
- On-grounds and public school based educational services.
- Private and semi-private rooms.
- Individualized programming designed to allow your family member to reach his/her full potential.
- In-house specialized equipment construction and equipment adaptation.
- Transportation in specially equipped vehicles.



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de los Angeles Inc.**

State Licensed/Federally Certified

1402 East South Mountain, Phoenix, AZ 85040
(602) 243-4231

William J. Timmons, Executive Director

HMS School

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- Occupational Therapy
- Speech and Language Therapy
- Communication Aids
- Special Education
- Music Therapy
- Special Medical Attention
- Adapted Recreational Activities

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:

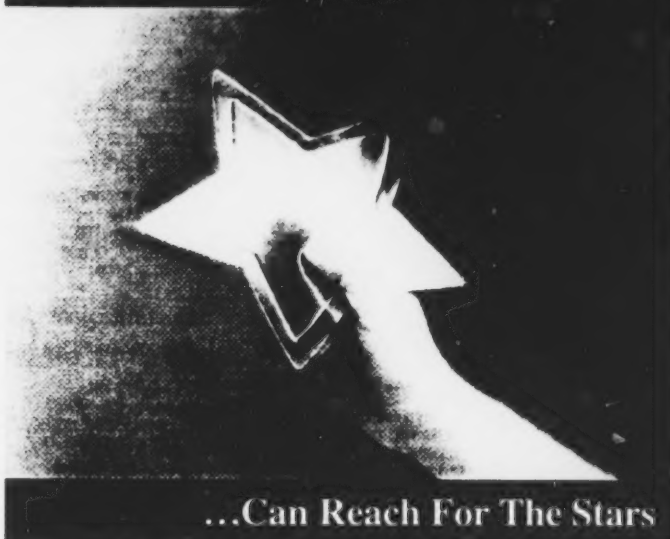
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy

4400 Baltimore Avenue, Philadelphia, PA 19104
(215) 222-2566



Even A "Wild" Child



Before 13-year-old Brian first came to Heartspring School, he was described as a "wild child," refusing to do even the simplest tasks. When pushed, Brian pushed back by hitting his ears, throwing chairs, even biting, clawing or pinching those around him. At times, four people could barely restrain him and Brian would retaliate by soiling himself over and over again. One such episode lasted more than three hours.

Brian's program at Heartspring achieved immediate results and have brought his behaviors almost completely under control. Today he can communicate his thoughts and feelings more easily. He is ready and willing to try new goals and he has discovered a talent for playing the drums.

His teachers use a simple sound recording of "white noise" to help Brian understand when a behavior is inappropriate and five-minute activities of Brian's choice to reinforce positive behaviors.

The program encourages Brian to "reach for the stars" — replacing inappropriate behaviors with more socially appropriate behaviors. With each day and each achievement, Brian is changing, growing and discovering that independence can be achieved without violence.

At Heartspring, we've been helping change the lives of children with special needs for more than fifty years. Our programs for children with behavior disorders are as unique as the children we serve. If you know a child with multiple disabilities who displays problem behaviors, call Heartspring today. Maybe we can help.



HEARTSPRING

FORMERLY THE INSTITUTE OF LOGOPEDICS
2400 JARDINE DRIVE WICHITA, KANSAS 67219-4699
316-262-8271 800-835-1043

430

Leigh's Disease

National Leigh's Disease Foundation
613 Childs Street
P.O. Box 2222
Corinth, MS 38834
(601) 287-8069, (601) 286-2551 (FAX)

Leprosy

American Leprosy Missions
1 ALM Way
Greenville, SC 29601
(800) 543-3131, (803) 271-7040
(803) 271-7062 (FAX)

Leukemia

Leukemia Society of America
600 Third Ave., 4th Floor
New York, NY 10016
(212) 573-8484, (212) 856-9686 (FAX)

Leukodystrophy

United Leukodystrophy Foundation
2304 Highland Drive
Sycamore, IL 60178
(800) 728-5483, (815) 895-3211
(815) 895-2432 (FAX)

Lissencephaly, Pachygyria and Agyria

Lissencephaly Network
716 Autumn Ridge Lane
Fort Wayne, IN 46804
(219) 432-4310

Liver Disorders

American Liver Foundation
1425 Pompton Ave.
Cedar Grove, NJ 07009
(800) 223-0179, (201) 256-3214

Lowe Syndrome

Lowe Syndrome Association
222 Lincoln St.
West Lafayette, IN 47906
(317) 743-3634

Lung Diseases

American Lung Association
1740 Broadway
New York, NY 10019
(212) 315-8700, (212) 265-5642 (FAX)

Lupus Erythematosus

The American Lupus Society
3914 Del Amo Blvd., Suite 922
Torrance, CA 90503
(800) 331-1802 (Info line)
(310) 542-8891

Lupus Foundation of America, Inc.
4 Research Place, Suite 180
Rockville, MD 20850-3226
(301) 670-9292, (800) 558-0121
(800) 558-0231 (Spanish)
(301) 670-9485 (FAX)

Lyme Disease

Lyme Disease Foundation
1 Financial Plaza
Gold Building, 18th Floor
Hartford, CT 06103
(203) 525-2000, (203) 525-8425 (FAX)

Macular Diseases

Association for Macular Diseases, Inc.
210 East 64th St.
New York, NY 10021
(212) 605-3719

Malignant Hyperthermia

Malignant Hyperthermia Association of United States (MHAUS)
P.O. Box 191
Westport, CT 06881-0191
(203) 847-0407, (203) 840-1772 (FAX)

Maple Syrup Urine Disease

Maple Syrup Urine Disease Family Support Group
8017 Jonestown Rd.
Harrisburg, PA 17112-9715
(717) 652-1386

Marfan Syndrome

National Marfan Foundation
382 Main Street
Port Washington, NY 11050
(800) 8-MARFAN
(516) 883-8712 (PHONE/FAX)

Medium-Chain Acyl-CoA Dehydrogenase Deficiency

Support Group for Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
805 Montrose Drive
Greensboro, NC 27410
(919) 547-0196

Mental Illness

Academy of Clinical Mental Health Counselors
5999 Stevenson Ave.
Alexandria, VA 22304
(703) 823-9800, ext. 384
(703) 823-0252 (FAX)

Federation of Families for Children's Mental Health
1021 Prince St.
Alexandria, VA 22314-2971
(703) 684-7710, (703) 684-7722
(703) 684-5968 (FAX)

National Mental Health Association
1021 Prince St.
Alexandria, VA 22314-2971
(800) 969-6642, (703) 684-7722
(703) 684-5968 (FAX)

Mental Retardation

The Arc (a national organization on mental retardation)
500 E. Border St., Suite 300
PO Box 1047
Arlington, TX 76010
(817) 261-6003, (800) 433-5255
(817) 277-0553 (TDD)
(817) 277-3491 (FAX)

Canadian Association for Community Living
4700 Keele St.
Kinsman Building
North York, ON Canada 437 7P3
(416) 661-9611, (416) 661-5701 (FAX)

Mental Retardation/ Mental Illness

National Organization of the Dually Diagnosed (NADD)
110 Prince Street
Kingston, NY 12401
(914) 331-4336, (800) 331-5362

Moebius Syndrome

Moebius Syndrome Support Group
39521 Rowen Court
Palmdale, CA 93551
(805) 267-2570

Mucopolysaccharidosis

National Mucopolysaccharidosis Society
17 Kraemer St.
Hicksville, NY 11801
(516) 931-6338, (516) 822-2041 (FAX)
Zain Hansen M.P.S. Foundation
P.O. Box 4768
Arcata, CA 95521
(800) 767-3121, (707) 822-5421

Multiple Sclerosis

National Multiple Sclerosis Society
733 3rd Ave.
New York, NY 10017
(800) 532-7667, (212) 986-3240
(212) 986-7981 (FAX)

Muscular Dystrophy

Muscular Dystrophy Association
3300 E. Sunrise Drive
Tucson, AZ 85718-3208
(602) 529-2000, (602) 529-5300 (FAX)

Myasthenia Gravis

Myasthenia Gravis Foundation (MGF)
53 W. Jackson Blvd., Suite 660
Chicago, IL 60604
(800) 541-5454, (312) 427-6252
(312) 427-8437 (FAX)

Myeloproliferative Disease

MPD Research Center, Inc.
2220 Tieman Ave.
Baychester, NY 10469
(800) HELP-MPD, (212) 697-5252

Myeloproliferative Disease Patient Network and Support Group
M.P.D. Research Center
2220 Tiemann Ave.
Baychester, NY 10469
(718) 231-0270, (718) 881-1905 (FAX)

Myoclonus

Myoclonus Families United
1564 East 34th St.
Brooklyn, NY 11234
(718) 252-2133

Nager and Miller Syndromes

Nager and Miller Syndromes Support
333 Country Lane
Glenview, IL 60025
(708) 724-6449

Narcolepsy

American Narcolepsy Association
425 California St., Suite 201
San Francisco, CA 94104
(415) 788-3303

Neurofibromatosis

National Neurofibromatosis Foundation
141 Fifth Avenue, Suite 7-S
New York, NY 10010-7105
(800) 323-7938, (212) 460-8980
(212) 529-6094 (FAX)

Neurological Disorders

National Institute of Neurological Disorders and Stroke
9000 Rockville Pike, Bldg. 31,
Rm. 8A-16
Bethesda, MD 20892
(301) 496-5751, (301) 402-2186 (FAX)

Neurometabolic Disorders

Association of Neurometabolic Disorders
5223 Brookfield Lane
Sylvania, OH 43560-1809
(419) 885-1497

Newborns with Illness

Parent Care, Inc.
9041 Colgate St.
Indianapolis, IN 46268-1210
(317) 872-9913

Niemann-Pick Disease

National Niemann-Pick Disease Foundation, Inc.
22201 Riverpoint Trail
Carrollton, VA 23314
(804) 357-6774

Noonan Syndrome

Noonan Syndrome Support Group
1278 Pine Ave.
San Jose, CA 95125
(408) 723-5188

Organic Acidemia

Organic Acidemia Association, Inc.
522 Lander St.
Reno, NV 89509
(702) 322-5542, (702) 323-3869 (FAX)

Orthopedic and Burn Problems

International Shriners Headquarters
2900 Rocky Point Drive
Tampa, FL 33607
(800) 282-9161 (in FL)
(800) 237-5055 (US)
(800) 361-7256 (CAN)
(813) 281-0300
(813) 287-8214 (FAX)

Osteogenesis Imperfecta

Osteogenesis Imperfecta Foundation, Inc.
5005 W. Laurel St., Suite 210
Tampa, FL 33607
(813) 282-1161, (813) 287-8214 (FAX)

Ostomy

United Ostomy Association
36 Executive Park, Suite 120
Irvine, CA 92714-6744
(800) 826-0826
(714) 660-8624, (714) 660-9262 (FAX)

Oxalosis & Hyperoxaluria

Oxalosis & Hyperoxaluria Found.
P.O. Box 1632
Kent, WA 98035
(206) 631-0386
(800) 484-9698 (#5100)

Pallister-Killian Syndrome

Pallister-Killian Family Support Group
4255 Fifth Ave. SW
Naples, FL 33999
(813) 455-0400

Parkinson Disease

National Parkinson Foundation
1501 Ninth Ave. NW
Miami, FL 33136
(800) 327-4545, (800) 433-7022 (in FL)
(305) 548-4403 (FAX)

Polymyositis & Dermatomyositis

National Support Group for Polymyositis & Dermatomyositis
P.O. Box 890
Cooperstown, NY 13326
(607) 547-5970

Porphyria

American Porphyria Foundation
P.O. Box 22712
Houston, TX 77227, (713) 266-9617

Prader-Willi Syndrome

Prader-Willi Syndrome Association
1821 University Ave. W. #N356
St. Paul, MN 55104
(800) 926-4797, (612) 641-1955
(612) 641-1952 (FAX)

Proteus Syndrome

Proteus Syndrome
805 E. 121st Terr.
Kansas City, MO 64146
(503) 244-7404, (503) 245-0626 (FAX)

Psoriasis

National Psoriasis Foundation
6600 SW 92nd, Suite 300
Portland, OR 97223
(301) 530-0354

Purine 24

Purine 24, Inc.
5424 Beech Ave.
Bethesda, MD 20814
(301) 530-0354

Reflex Sympathetic Dystrophy Syndrome

Reflex Sympathetic Dystrophy Association
116 Haddon Ave., Suite D
Haddonfield, NJ 08033
(609) 795-8845 (phone/FAX)

Rett Syndrome

International Rett Syndrome Association
9121 Piscataway Rd., Suite 2B
Clinton, MD 20735
(301) 856-3334

Rubinstein-Taybi Syndrome

Rubinstein-Taybi Parent Group
P.O. Box 146
Smith Center, KS 66967
(913) 697-2984

Russell-Silver Syndrome

Association for Children with
Russell-Silver Syndrome
22 Hoyt St., Madison, NJ 07940
(201) 377-4531, (201) 822-2715 (FAX)

Scoliosis

National Scoliosis Foundation
72 Mount Auburn St.
Watertown, MA 02172
(617) 926-0397, (617) 926-0398 (FAX)

Seizure Disorder

THRESHOLD—Intractable Seizure
Disorder Support Group
26 Stavola Road
Middletown, NJ 07748-3728
(908) 957-0714

Short Stature

Little People of America, Inc.
P.O. Box 9897
Washington, DC 20016
(800) 24D-WARF

Sickle Cell Disease

National Association for Sickle Cell
Disease (NASCD)
3345 Wilshire Blvd., Suite 1106
Los Angeles, CA 90010-1880
(800) 421-8453, (213) 736-5455
(213) 736-5211 (FAX)

Skin (Dermatological) Disorders

National Alopecia Areata
Foundation
710 C Street, Suite 11
San Rafael, CA 94904
(415) 456-4644, (415) 456-4274 (FAX)

Dystrophic Epidermolysis Bullosa
Research Association (D.E.B.R.A.)
141 Fifth Ave., Ste. 7-S
New York, NY 10010
(212) 995-2220

Foundation for Ichthyosis and
Related Skin Types (F.I.R.S.T.)
P.O. Box 20921
Raleigh, NC 27619-0921
(800) 545-3286, (919) 782-5728
(919) 781-0679 (FAX)

Scleroderma Federation
Peabody Office Building
One Newbury St.
Peabody, MA 01960
(508) 535-6600, (508) 535-6696 (FAX)

United Scleroderma Foundation
P.O. Box 399
Watsonville, CA 95077-0399
(800) 722-HOPE
(408) 728-2202, (408) 728-3328 (FAX)

National Vitiligo Foundation
P.O. Box 6337
Tyler, TX 75711
(903) 534-2925, (903) 534-8075 (FAX)

Xeroderma Pigmentosum Registry
(UMDNJ)
New Jersey Medical School
Dept. of Pathology, Room C-520
Medical Science Building
185 S. Orange Ave
Newark, NJ 07103-2714
(201) 982-6255

Sotos Syndrome

Sotos Syndrome U.S.A. Support
Association (SSSA)
937 Shandra Drive
Ballwin, MO 63021
(314) 256-0156

Spina Bifida

Spina Bifida Association of America
4590 MacArthur Blvd. NW #250
Washington, DC 20007-4226
(800) 621-3141
(202) 944-3285, (202) 944-3295 (FAX)

Spina Bifida Association of Canada
220-388 Donald Street
Winnipeg, MB Canada R3B 2J4
(204) 957-1794

Spinal Cord Injuries

National Spinal Cord Injury Assoc.
600 W. Cummings Pk., Suite 2000
Woburn, MA 01801
(617) 935-2722
(800) 962-9629 (hotline only)
(617) 932-8369 (FAX)

American Paralysis Spinal Cord
Hotline
2201 Argonne Drive
Baltimore, MD 21218
(800) 526-3456

American Paralysis Association
500 Morris Avenue
Springfield, NJ 07081
(800) 225-0292, (201) 379-2690 (in NJ)
(201) 912-9433 (FAX)

Spinal Muscular Atrophy

Families of S.M.A.
P.O. Box 1465
Highland Park, IL 60035-7465
(800) 886-1762
(708) 432-5551 (phone/FAX)

Sturge-Weber Syndrome

Sturge-Weber Foundation
P.O. Box 460931
Aurora, CO 80046
(800) 627-5482, (303) 360-7290
(303) 699-1406 (FAX)

Stuttering

National Center for Stuttering
200 East 33rd St.
New York, NY 10016
(800) 221-2483

National Stuttering Project
2151 Irving St., Suite 208
San Francisco, CA 94122-1609
(800) 364-1677, (415) 566-5324

Stuttering Foundation of America
P.O. Box 11749
Memphis, TN 38111-0749
(800) 992-9392, (202) 363-3199
(901) 452-3931 (FAX)

Sudden Infant Death Syndrome (SIDS)

National Sudden Infant Death
Syndrome (SIDS) Alliance, Inc.
10500 Little Patuxent Pkwy. #420
Columbia, MD 21044-3505
(800) 221-SIDS, (410) 964-8000

The New England Center for Autism is dedicated to providing the most caring, comprehensive, and innovative education

available today to children with autism and mental retardation.

Our behaviorally oriented, community-based center, serving students aged 3 to adult, has revolutionized the way in which children with autism and developmental disabilities are cared for and educated. At admission, these students have severe behavioral problems including aggression, self-injurious behavior and hyperactivity. Half of our students have seizure disorders.

Our educational facility is located in Southboro, Massachusetts, with 12 attractive student homes in nearby neighborhoods. Our professional staff includes clinical psychologists, special educators, social workers, nurses and physicians. Appropriate students are welcomed from all over the U.S.

For more information, please contact
Vincent Strully, Jr., Executive Director.

33 Turnpike Road • Southboro, MA 01772 • (508) 481-1015 • Just 20 miles west of Boston

Children of Promise



"I want to thank
The Center's staff for
the foresight, persistence
and expertise in executing
perhaps the finest program
for autistic children and
adults in the nation."

Barbara C. Fries,
parent

The
New England
Center for
Autism, Inc.

Tay-Sachs Disease

National Tay-Sachs and Allied Diseases Association

2001 Beacon St., Suite 204
Brookline, MA 02146
(617) 277-4463, (617) 277-0134 (FAX)

Technology-Dependent

Sick Kids Need Involved People (SKIP)
216 Newport Drive
Severna Park, MD 21146
(410) 379-0999

Terminal Illness

Children's Hospice International
901 N. Washington Street, Suite 700
Alexandria, VA 22314
(800) 242-4453, (703) 684-0330

Thrombocytopenia Absent Radius Syndrome

Thrombocytopenia Absent Radius Syndrome Association (TARSA)
212 Sherwood Drive, RD 1
Linwood, NJ 08221-9745
(609) 927-0418

Tourette Syndrome

Tourette Syndrome Association
42-40 Bell Blvd.
Bayside, NY 11361-2861
(800) 237-0717, (718) 224-2999
(718) 279-9596 (FAX)

Treacher Collins Disease

Treacher Collins Foundation
P.O. Box 683
Norwich, VT 05055
(802) 649-3020

Tuberous Sclerosis

National Tuberous Sclerosis Assoc.
8000 Corporate Drive Suite 120
Landover, MD 20785
(800) 225-NTSA, (301) 459-9888
(301) 459-0394 (FAX)

Turner's Syndrome

The Turner's Syndrome Society
7777 Keele St., Floor 2
Concord, ON Canada L4K 1Y7
(416) 660-7766, (416) 660-7450 (FAX)

Urea Cycle Disorders

National Urea Cycle Disorders Found.
4559 Vauxhall Road
Richmond, VA 23234
(908) 851-2731

Vestibular Disorders

Vestibular Disorders Associations
P.O. Box 4467
Portland, OR 97208-4467
(503) 229-7705

Visual Impairments

Retinitis Pigmentosa International Society for Degenerative Eye Diseases
P.O. Box 900
Woodland Hills, CA 91365
(800) 344-4877, (818) 992-0500

RP Foundation Fighting Blindness

1401 Mt. Royal Ave., 4th Floor
Baltimore, MD 21217
(800) 683-5555, (410) 225-9400
(410) 225-9409 (TTD)
(410) 225-3936 (FAX)

National Retinoblastoma Parent Group

603 Fourth Range Road
Pembroke, NH 03275
(603) 224-4085

Stargardt Disease Self-Help Network

P.O. Box 136
West Chicago, IL 60186
(708) 208-5017

American Council of the Blind

1155 15th St. NW, Suite 720
Washington, DC 20005
(800) 424-8666, (202) 467-5081

American Foundation for the Blind

15 W. 16th St.
New York, NY 10011
(800) AFB-LINE
(212) 620-2147 (in NY only)

Blind Children's Center

4120 Marathon St.
Los Angeles, CA 90029-0159
(800) 222-3566

Blind Children's Fund

8500 W. Capitol Drive
Milwaukee, WI 53222
(414) 464-3000 (414) 464-5693 (FAX)

Canadian National Institute for the Blind

1929 Bayview Ave.
Toronto, ON Canada M4G 3E8
(416) 480-7415, (416) 480-7414
(416) 480-7699 (FAX)

National Association for Parents of the Visually Impaired

P.O. Box 317
Watertown, MA 02272-0317
(800) 562-6265

National Association for Visually Handicapped

22 West 21st Street, 6th Floor
New York, NY 10010
(212) 889-3141, (202) 727-2931 (FAX)

National Federation of the Blind

1800 Johnson St.
Baltimore, MD 21230
(410) 659-9314, (410) 752-5011 (BBS)

Vision Foundation

818 Mt. Auburn St.
Watertown, MA 02172
(800) 852-3029 (in MA), (617) 926-4232

Institute for Families of Blind Children

P.O. Box 54700, Mail Stop #111
Los Angeles, CA 90054
(213) 669-4649

National Society to Prevent Blindness

500 E. Remington Rd.
Schaumburg, IL 60173-4557
(800) 331-2020, (708) 843-2020
(708) 843-8458 (FAX)

Recording for the Blind

20 Roszel Rd., Princeton, NJ 08540
(609) 452-0606

American Printing House for the Blind

1839 Frankfort Ave.
P.O. Box 6085
Louisville, KY 40206-0085
(800) 223-1839
(502) 895-2405, (502) 895-1509 (FAX)

Von Hippel-Lindau Syndrome

VHL (Von Hippel-Lindau Syndrome) Family Alliance

171 Clinton Rd.
Brookline, MA 02146
(617) 232-5946 (evenings)
(617) 734-8233 (FAX)

Providing Quality Services for Children and Adults
with Autism and Related Developmental Disabilities



Day

Early Intervention Age 22

Residential

Ages 6-22

Farmstead

Age 18 - Adulthood

Twelve-Month Day Educational Programming

Specialized Community Residences

Early Intervention and Home Training

Community-Based Supportive Employment and Vocational Training

After-School Recreational Programs

Friendship Farms Adult Farm Living in the Heart of Cranberry Country

League School of Boston, Inc.

225 Nevada Street
Newtonville, MA 02160
(617) 964-3260

Herman T. Fishbein
Executive Director

Accreditation: Massachusetts Dept. of Education, Office for Children, Dept. of Social Services, Dept. of Mental Retardation, Dept. of Mental Health, NY Dept. of Education

THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities

and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.



new england villages, inc.

A Model, Supportive Community
For Mentally Retarded Adults

664EP School Street, Pembroke, MA 02359 (617) 293-5461

Wegener Granulomatosis

Wegener Granulomatosis Support Group, Inc.
P.O. Box 1518
Platt City, MO 64079-1518
(816) 431-2096, (800) 277-9474

Williams Syndrome

Williams Syndrome Association
P.O. Box 3297
Ballwin, MO 63022-3297
(314) 227-4411

Wilson's Disease

Wilson's Disease Association
P.O. Box 75324
Washington, DC 20013
(703) 636-3003, (703) 636-3014

Wolf-Hirshhorn Syndrome (4p-)

4p- Parents Group
3200 Rivanna Court
Woodbridge, VA 22192
(703) 491-0309

Wolf-Hirshhorn Syndrome (4p-)
Support Group and Newsletter
5536 Virginia Ct.
Amherst, OH 44001
(216) 282-1460



Behavior Disorders Program

The New England Center For Autism serves a number of pre-teen and teenage students who have only mild to moderate cognitive deficits but present significant challenging behaviors secondary to emotional disturbances and psychiatric disorders.

The New England Center is a behaviorally oriented community-based center serving students aged 3 to adult. All students participate in a full range of educational, vocational and community-based leisure activities. Our active vocational program provides supported employment opportunities for students 16 and over and our central facility serves as the educational site for all students.

In addition to a first-rate teaching and educational staff, The New England Center has comprehensive in-house medical, psychiatric, nursing and clinical psychology services available. Our goal is to provide the best educational environment for behaviorally challenging children regardless of their diagnoses or the etiology of their problems.

The Center's full range of services is available 24-hours a day, 365 days a year.

For more information, please contact Vincent Strully, Jr., Executive Director.

**The New England
Center for
Autism, Inc.**

33 Turnpike Road • Southboro, MA 01772 • (508) 481-1015
Just 20 miles from Boston.



Special Care for Special People

Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 600-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or
write for brochure

THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601

John P. Stewart, M.D., Resident Physician



Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1947, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

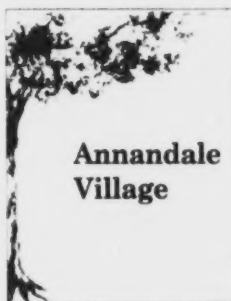
Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615



"THEIR COMMUNITY ... WITH OUR HELP" Private, nonprofit community for adults with developmental disabilities. Residential and day/evening programs and services.

- Paid Job Training
- Arts Activities.
- Therapeutic recreation.
- Case management.
- 125-acre wooded environment.

Annandale at Suwanee, Inc.
3500 Annandale Lane, Box 7
Suwanee, GA 30174
(404) 945-8381



CHILED A HABILITATION INSTITUTE. Educators for children with developmental disabilities. Residential treatment center provides complete training & intensive therapy for children with severe mental & physical disabilities, closed head injuries & challenging behaviors. Estab. 1973.

- Intensive
- Progressive
- Specialized

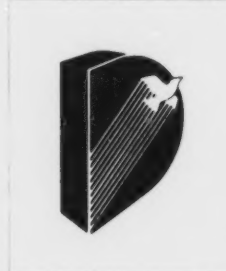
Chileda Habilitation Institute
1020 Mississippi Street
LaCrosse, WI 54601
(608) 782-6480/(608) 782-6481(Fax)



BARTLETT LEARNING CENTER
For students, 3-21 yrs., with learning disabilities, developmental disabilities or behavior problems. Range of options:

- Full academic day school with summer session, 12-mo. residential facility
- Post-graduate assistance (job and living placement)
- Group home for dev. disabled men 18-40 yrs.
- 75-acre campus NW of Chicago.

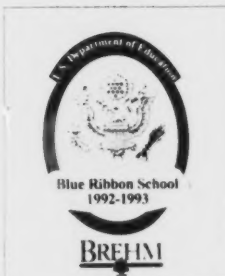
Bartlett Learning Center
801 W. Bartlett Road
Bartlett, IL 60103
(708) 289-4221



WORKING TOGETHER FOR A BETTER FUTURE! In residential, day and community-based treatment centers nationwide, Devereux provides comprehensive services to individuals of all ages who have:

- Emotional disturbances.
- Developmental disabilities.
- Mental retardation • Dual diagnosis.
- Autism • Post-head trauma.

Contact: National Referral Services
The Devereux Foundation
(800) 345-1292, ext. 3045
(215) 964-3045
(215) 971-4600 (FAX)



1993 BLUE RIBBON WINNER
Brehm Preparatory School is a residential school designed to meet the academic, social and emotional requirements of adolescents (age 12-21) with learning disabilities. Brehm offers specialized academic instruction, Orton training, speech and language therapy and social skills guidance. Certified staff. Family atmosphere. NCA Accredited

Brehm Preparatory School
1245 East Grand Ave.
Carbondale, IL 62901
(618) 457-0371



THE DUVALL HOME, EST. 1945. A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory people with mental retardation of all ages.

- 24-hour nursing care.
- Lovely 24-acre rural campus.
- Recreational and training activities.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 36
Glenwood, FL 32722
(904) 734-2874



A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:

- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 31st year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
P.O. Box 3789
Poughkeepsie, NY 12603
(914) 687-7840



ELWYN, INC. Caring for over 10,000 children and adults with varying disabilities, offers transitional services from school to work, 24 hr. health care, award-winning therapeutic recreation programs, early intervention with elementary and secondary education, vocational training and placements. Modern, home-like residential settings in Pennsylvania, Delaware, New Jersey, California, and Jerusalem, Israel.

Contact: Admissions Office
Elwyn, Inc.
111 Elwyn Road
Elwyn, PA 19063-4699
(215) 891-2024/(800) 345-8111

Parent Training and Information Centers

This program views parents as full partners in the educational process and a significant source of support and assistance to each other. The following PTIs are funded by the Division of Special Education Program (OSEP), U.S. Dept. of Education, "to provide training and information to parents to enable such individuals to participate more effectively with professionals in meeting the educational needs of handicapped children" as stated in PL 98-199.

Alabama

Special Education Action Committee, Inc. (SEAC)
P.O. Box 161274
Mobile, AL 36616-2274
(205) 478-1208, (800) 222-7322
(205) 473-7877 (FAX)

Alaska

Alaska PARENTS Resource Center
(Parents as Resources Engaged in Networking & Training Statewide)
540 International Airport Rd.
Suite 250
Anchorage, AK 99518
(907) 563-2246, (800) 478-7678
(907) 790-2248 (FAX)

Arizona

Pilot Parent Partnerships
2150 East Highland Ave.
Suite 105
Phoenix, AZ 85016
(602) 468-3001, (800) 237-3007

Arkansas

Arkansas Disability Coalition
10002 West Markham, Suite B7
Little Rock, AR 72205
(501) 221-1330 (voice/TDD)
(501) 221-9067

FOCUS, Inc.
2917 King Street, Suite C
Jonesboro, AR 72401
(501) 935-2750
(501) 221-1330 (voice/TDD)
(501) 931-1111 (FAX)

California

Team of Advocates for Special Kids, Inc. (TASK)
100 W. Cerritos Ave.
Anaheim, CA 92805-6546
(714) 533-TASK, (714) 533-2533 (FAX)

Parents Helping Parents
1801 Vincente St.
San Francisco, CA 94116
(415) 564-0722
(415) 681-1065 (FAX)

Northern Coalition for Parent Training and Information (NCC)

Parents Helping Parents
535 Race Street, Suite 140
San Jose, CA 95126
(408) 288-5010
(408) 288-7493 (FAX)

DREDF
2212 6th Street
Berkeley, CA 94710
(510) 644-2555
(510) 841-8645 (FAX)

Matrix, A Parent Network and Resource Center
P.O. Box 6541
San Rafael, CA 94903
(415) 499-3877
(415) 499-3864 (FAX—call first)

Exceptional Parents Unlimited
4120 No. 1st Street
Fresno, CA 93726
(209) 229-2000
(209) 229-2956 (FAX)

Colorado

PEAK Parent Center, Inc.
6055 Lehman Dr., Suite 101
Colorado Springs, CO 80918
(719) 531-9400
(719) 531-9403 (TDD)
(800) 284-0251
(719) 531-9452 (FAX)

Connecticut

CT Parent Advocacy Center, Inc. (CPAC)
5 Church Lane, Suite #4
P.O. Box 579
East Lyme, CT 06333
(203) 739-3089, (800) 445-2722
(203) 739-7460 (FAX)

Delaware

Parent Information Center of Delaware, Inc.
700 Barksdale Road, Suite 6
Newark, DE 19711
(302) 366-0152
(302) 366-0178 (TDD)
(302) 366-0276 (FAX)

District of Columbia

COPE
P.O. Box 90498
Washington, DC 20090-0498
(202) 526-6814, (202) 832-2180 (FAX)

Florida

Family Network on Disability
5510 Gray Street, Suite 220
Tampa, FL 33609
(813) 289-1122 (Voice/TDD)
(813) 286-8614 (FAX)

Georgia

Parents Educating Parents (PEP) Georgia ARC
1851 Ram Runway, Suite 104
College Park, GA 30337
(404) 761-2745 (Voice/TDD)
(404) 761-3150, (800) 966-3150
(404) 767-2258 (FAX)

Hawaii

AWARE/Learning Disabilities Association of Hawaii (LDAH)
200 North Vineyard Blvd., Suite 103
Honolulu, HI 96817
(808) 536-2280 (Voice/TDD)
(808) 543-2222 (FAX)

Idaho

Idaho Parents Unlimited, Inc. Parent Education Resource Center
4696 Overland Road, Suite 478
Boise, ID 83705
(208) 342-5884 (Voice/TDD)
(800) 242-IPUL
(208) 342-1408 (FAX)

Illinois

Family Resource Center on Disabilities (FRCD)
20 East Jackson Blvd., Room 900
Chicago, IL 60604
(312) 939-3513
(312) 939-3519 (TDD/TTY)
(800) 952-4199, (312) 939-7297 (FAX)

Designs for Change
220 S. State Street, Suite 1900
Chicago, IL 60604
(312) 922-0317, (800) 952-4199
(312) 922-6993 (FAX)

Indiana

Indiana Resource Center For Families with Special Needs (IN-SOURCE)
833 E. Northside Blvd., Building 1, Rear
South Bend, IN 46617
(219) 234-7101, (800) 332-4433
(219) 287-9651 (FAX)

Iowa

Iowa Pilot Parents (IEPC)
33 North 12th Street
P.O. Box 1151
Fort Dodge, IA 50501
(515) 576-5870
(800) 952-4777 (parents only)
(515) 576-8209 (FAX)

Kansas

Families Together, Inc.
1023 S.W. Gage Blvd.
Topeka, KS 66604
(913) 273-6343, (800) 264-6343
(913) 273-1385 (FAX)

Kentucky

Kentucky Special Parent Involvement Network (KY-SPIN)
2210 Goldsmith Lane, Ste 118
Louisville, KY 40218
(502) 456-0923, (800) 525-7746
(502) 456-0893

Louisiana

Program of Families Helping Families of Greater New Orleans
4323 Division Street, Ste 110
Metairie, LA 70002-3179
(504) 888-9111, (800) 766-7736
(504) 888-0246 (FAX)

Maine

Special-Needs Parent Information Network (SPIN)
P.O. Box 2067
Augusta, ME 04338
(207) 582-2504, (800) 325-SPIN
(207) 582-5022 (FAX)

Maryland

Parents Place of MD, Inc.
7257 Parkway Drive, Suite 210
Hanover, MD 21076
(410) 712-0900 (Voice/TDD)
(410) 712-0902 (FAX)

Massachusetts

Federation for Children with Special Needs, Inc.
95 Berkeley Street, Suite 104
Boston, MA 02116
(617) 482-2915, (800) 331-0688
(617) 695-2939 (FAX)

Michigan

Parents are Experts: Parents Training Parents Project
23077 Greenfield Rd., Ste 205
Southfield, MI 48075-3744
(313) 557-5070 (Voice/TDD)
(313) 557-4456 (FAX)

Citizens Alliance to Uphold Special Education (CAUSE)
313 So. Washington Sq. Ste 040
Lansing, MI 48933
(517) 485-4084 (Voice/TDD)
(800) 221-9105, (517) 485-4145 (FAX)

Minnesota

PACER Center, Inc.
4826 Chicago Avenue South
Minneapolis, MN 55417
(612) 827-2966
(800) 53P-ACER (parents only)
(612) 827-3065 (FAX)

Mississippi

Association of Developmental Organizations of Mississippi (ADOM)
332 New Market Drive
Jackson, MS 39209
(601) 922-3210, (800) 898-1026
(601) 922-6854 (FAX)

Missouri

Missouri Parents Act (MPACT)
1722W South Glenstone,
Suite 125
Springfield, MO 65804
(417) 882-7434 (Voice/TDD)
(800) 743-7634
(417) 882-8413 (FAX)

MPACT—Kansas City Office
1115 E. 65th Street
Kansas City, MO 64131
(816) 333-6833 (Voice)
(816) 333-5685 (TDD)
(816) 333-2267 (FAX)

MPACT—St. Louis Office
8631 Delmar, Suite 300
St. Louis, MO 63124
(314) 997-7622 (Voice/TDD)
(800) 995-3160, (314) 997-5518 (FAX)

The Groden Center

THE GRODEN CENTER Nationally recognized education & treatment facility serving children & young adults with autism & other developmental disabilities. Highly trained, devoted staff provide academic, vocational, supported employment programs, relaxation, imagery & other positive self-control techniques.

The Groden Center, Inc.
86 Mount Hope Ave.
Providence, RI 02906
(401) 274-6310



Martha Lloyd Community Services

MARTHA LLOYD COMMUNITY SERVICES Quality services for persons w/ Prader Willi Syndrome. Successfully manages the unique nutritional dietary needs & social and emotional challenges common to this disorder. Support systems to enable greater self-management in diet, behavior & personal responsibility. Academic, vocational training, social & recreational. N. central Pennsylvania.

Martha Lloyd Community Services
190 West Main Street
Troy, PA 16947
(717) 297-2185

THE KOLBURN SCHOOL

Residential
Special Education
School and
Treatment Center

THE KOLBURN SCHOOL INC. A coed Residential Treatment Center providing a safe, structured, warm therapeutic environment for students ages 8-24 who are:

- Emotionally Disturbed
 - Learning Disabled
 - Neurologically Impaired
 - Head Trauma Victims (Ambulatory)
- Offers a wide spectrum of rehabilitative services. For more information:

The Kolburn School
Southfield, Road
New Marlborough, MA 01230
(413) 229-8787

The Rugby School

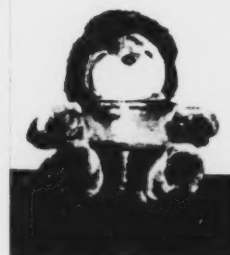
JUST A BIT OF OUR PHILOSOPHY :
To heighten abilities and possibilities... To help students discover their hidden resources... To recognize that children learn in different ways... To foster pride by expecting a lot from the youth entrusted to our care...

Contact: Donald Desanto, Director
The Rugby School
Belmar Blvd. & Woodfield Ave
P.O. Box 1403
Wall, NJ 07719
(908) 681-6900



LEAGUE SCHOOL OF BOSTON, INC. Day & residential school for children & young adults 3-22 years of age with Autism & related developmental disabilities. Vocational program on-site job training. School utilizes psycho-educational approach, focusing on areas of language, social cognitive, emotional & behavioral development. Educational, residential, vocational & therapeutic services. 20-acre adult farmstead.

League School of Boston, Inc.
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260 FAX (617) 964-3264



SUNRISE REHABILITATION HOSPITAL. An individualized pediatric adolescent prog. offering a interdisciplinary team approach to specialized rehab. care following accidents or acute illness.

- Medical direction by a pediatric physiatrist.
- Inpatient programs for continued therapy.
- Particular expertise in rehab. of ventilator patients and coma recovery.
- Many disabilities served.

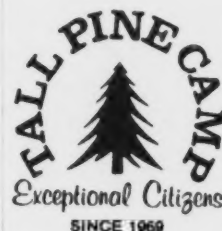
Sunrise Rehabilitation Hospital
(800) 648-9111 (800) 634-9111



"MAXIMIZING INDIVIDUAL POTENTIAL"

- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000



TALL PINE CAMP. Co-ed mountain camping for children and adults with MR. Programs and activities based on individual abilities. Prof. staff, two full-time nurses. Self-care & social skills emphasized. Academics, incl. computer programming. Many recreational activities including: swimming, crafts, boating, equestrian prog., etc. 2, 3, 6 wk. sessions available for \$300/wk.

Contact: Ron & Camarie Eydt
Tall Pine Camp, Rt. 2, Box 194-A
Tellico Plains, TN 37385
(615) 261-2329

Daring to dream with Elwyn...



"When Alice was small, we dreamed of a place where her opportunities to learn would be unlimited by labels. A place where she would get the specialized care she needed ... a place where we and her teachers could develop her talents and skills together. And we did."

"When Carla got her first job, my wife and I thought she had everything we could hope for. Then she surprised us and said, Dad, I want a place of my own. Suddenly we had a new dream — one that required help and continuing support. We knew who we could turn to for that help."



Here's some of what Elwyn offers:

- *transitional services from school to work*
 - *award-winning therapeutic recreation programs*
 - *24-hour health care services*
 - *early intervention, elementary and secondary education*
 - *vocational training and placement*
 - *modern, homelike residential settings*
-

Elwyn, caring for over 10,000 children and adults with varying disabilities, has locations throughout Pennsylvania, Delaware, New Jersey, California, and Jerusalem, Israel.

"The Elwyn Story: Love and Much More" videotape available upon request

Elwyn, Inc.

Contact: The Admissions Office
111 Elwyn Road

Elwyn, Pennsylvania 19063-4699

Telephone: (215) 891-2040 (PA) (800) 345-8111 (Outside PA)

Montana

Parents Let's Unite for Kids (PLUK)
EMC/Special Education Building
1500 North 30th Street
Billings, MT 59101-0298
(406) 657-2055, (800) 222-7585
(406) 657-2061 (FAX)

Nebraska

Nebraska Parents' Center
3610 Dodge Street
Omaha, NE 68131
(402) 346-0525 (Voice/TDD)
(800) 284-8520, (402) 346-5253 (FAX)

Nevada

Nevada Parent Connection
3380 S. Arville Blvd.
Las Vegas, NV 89102
(702) 252-0259 (X112)
(702) 252-8780 (FAX)

New Hampshire

Parent Information Center
151A Manchester Street
P.O. Box 1422
Concord, NH 03302-1422
(603) 224-6299
(603) 224-7005 (Voice/TDD)
(800) 232-0986, (603) 224-4365 (FAX)

New Jersey

Statewide Parent Advocacy Network, Inc. (SPAN)
516 North Avenue East
Westfield, NJ 07090
(908) 654-7726, (800) 654-SPAN
(908) 654-7880 (FAX)

New Mexico

EPICS Project
S.W. Communication Resources, Inc.
P.O. Box 788
2000 Camino del Pueblo
Bernalillo, NM 87004
(505) 867-3396 (Voice, TDD)
(800) 767-7320 (Voice, TDD)
(505) 867-3398 (FAX)

Parents Reaching Out
1127 University Blvd. NE
Albuquerque, NM 87102
(505) 842-9045 (Voice/TDD)
(800) 524-5176
(505) 842-1451 (FAX)

New York

Parent Network Center (PNC)
1443 Main Street
Buffalo, NY 14209
(716) 885-1004, (800) 724-7408
(716) 885-9597 (FAX)

Advocates for Children of New York, Inc.
24-16 Bridge Plaza South
Long Island City, NY 11101
(718) 729-8866
(718) 729-8931 (FAX)

Resources for Children with Special Needs
200 Park Avenue South, Ste 816
New York, NY 10003
(212) 677-4650
(212) 254-4070 (FAX)

North Carolina

Exceptional Children's Assistance Center (ECAC)
P.O. Box 16
Davidson, NC 28655
(704) 892-1321
(800) 962-6817
(704) 892-5028 (call first)

Parents Project
300 Enola Road
Morganton, NC 28655
(704) 433-2662
(704) 438-6457 (FAX)

North Dakota

Pathfinder Family Center
1600 Second Ave. SW
Minot, ND 58701
(701) 852-9426
(701) 852-9436 (TDD)
(800) 245-5840
(701) 838-9324 (FAX)

Ohio

Child Advocacy Center
1821 Summit Road, Suite 303
Cincinnati, OH 45237
(513) 821-2400
(513) 821-2442 (FAX)

Ohio Coalition for the Education of Handicapped Children (OCEHC)
1299 Campbell Road, Suite B
Marion, OH 43302
(614) 382-5452 (Voice/TDD)
(800) 374-2806
(614) 382-2399 (FAX)
(614) 431-1307 (Worthington office)

Oklahoma

Parents Reaching Out in Oklahoma Project (PRO-OK)
1917 South Harvard Avenue
Oklahoma City, OK 73128
(405) 681-9710 (Voice/TDD)
(800) PL9-4142
(405) 685-4006 (FAX)

Oregon

Oregon COPE Project, Inc.
999 Locust Street, NE Box B
Salem, OR 97303
(503) 373-7477 (Voice/TDD/FAX)

Pennsylvania

Parents Union for Public Schools
311 South Juniper Street,
Suite 602
Philadelphia, PA 19107
(215) 546-1166
(215) 731-1688 (FAX)

Mentor Parent Program
Route 257, Salina Road
P.O. Box 718
Seneca, PA 16346
(814) 676-8615
(800) 447-1431
(814) 676-8615 (FAX)

Parent Education Network
333 E. 7th Avenue
York, PA 17404
(717) 845-9722 (Voice/TDD)
(800) 522-5817 (Voice/TDD)
(800) 441-5052 (Spanish)
(717) 848-3654 (FAX)

Puerto Rico

Asociación de Padres Por Bienestar de Niños Impedidos de PR, Inc.
P.O. Box 21301
Rio Piedras, PR 00928-1301
(809) 763-4665, (809) 765-0345

Rhode Island

Rhode Island Parent Information Network (RIPIN)
Independence Square
500 Prospect Street
Pawtucket, RI 02860
(401) 727-4144, (401) 725-9960 (FAX)

South Carolina

PRO-PARENTS
2712 Middleburg Drive, Ste 102
Columbia, SC 29204
(803) 779-3859 (Voice/TDD)
(800) 759-4776, (803) 252-4513 (FAX)

South Dakota

South Dakota Parent Connection
P.O. Box 84813
Sioux Falls, SD 57118-4813
(605) 335-8504 (Voice/TDD)
(800) 640-4553
(605) 335-8504 (FAX)

Tennessee

Support & Training for Exceptional Parents (STEP)
1805 Hayes Street, Suite 100
Nashville, TN 37203
(615) 639-0125
(800) 280-STEP
(800) 848-0298 (TDD)
(615) 327-0827 (FAX)

Texas

Partners Resource Network, Inc.
PATH
227 North 18th, #2
Beaumont, TX 77707-2203
(409) 838-2366, (800) 866-4726
(409) 866-2351 (FAX)

Special Kids, Inc. (SKIP)
P.O. Box 61628
Houston, TX 77208-1628
(713) 643-9576, (713) 643-6291 (FAX)

Project PODER
2300 West Commerce, Suite 205
San Antonio, TX 78207
(210) 732-8247
(800) 682-9747
(210) 732-8249 (FAX)

Utah

Utah Parent Center
2290 East 4500 South
Suite 110
Salt Lake City, Utah 84117
(801) 272-1051
(800) 468-1160
(801) 272-3479 (FAX)

Vermont

Vermont Parent Information Center (VPIC)
The Chase Mill
1 Mill Street
Burlington, VT 05401
(802) 655-4016 (Voice, TDD)
(800) 639-7170
(802) 655-5976 (FAX)

Virginia

Parent Educational Advocacy Training Center (PEATC)
228 South Pitt Street, Suite 300
Alexandria, VA 22314
(703) 836-2953
(703) 836-3026 (TDD)
(800) 869-6782 (VA, WV, MD)
(703) 836-5869 (FAX)

Washington

Washington PAVE
6316 South 12th Street
Tacoma, WA 98465
(206) 565-2266 (Voice/TDD)
(800) 5PA-RENT
(206) 566-8052 (FAX)

PAVE/STOMP
Specialized Training of Military Parents
12208 Pacific Highway SW
Tacoma, WA 98499
(206) 588-1741 (Voice/TDD)
(206) 984-7520 (FAX)

A Touchstones Program

6721 51st Avenue South
Seattle, WA 98118
(206) 721-0867
(206) 721-2422 (FAX)

West Virginia

West Virginia PTI
104 East Main Street
Suite 3-B
Clarksburg, WV 26301
(304) 624-1436 (Voice/TDD)
(304) 622-5861 (FAX)

Wisconsin

Parent Education Project of WI, Inc. (PEP-WI)
2001 West Vliet Street
Milwaukee, WI 53205
(414) 937-8380
(800) 231-8382
(414) 933-6077 (FAX)

Wyoming

Wyoming PIC
5 North Lobban
Buffalo, WY 82834
(307) 684-2277 (Voice/TDD)
(800) 660-WPIC
(307) 684-5314 (FAX)



Berkshire Meadows - a place of "small miracles"

Hot water swirls and churns, limbs relax, movement eases. A child smiles. Soothed and buoyed by the bubbling warmth, he responds as his arms and legs are gently stretched, pushing against the flow of the water, relaxing back with it, each movement broader, smoother than the last.



Young bodies float in a broad expanse of bath-tub-warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex; laughter at splashes and water-antics; shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

The little boy described above does not wear a daytime brace to maintain his range of movement. Instead, once a week, he experiences the intense relaxation of the Hubbard tank. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more coordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young man in the therapeutic pool will also experience a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a movable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the children, when in the pool, to move in ways in which otherwise they cannot: if they cannot walk on land owing to poor strength or joint pain, they might be able to walk independently when in the water, or they might acquire real movement, instead of spasticity. Here, in the pool's supportive warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced - and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multi-faceted program at Berkshire Meadows, a private, non-profit residential school for children and adolescents who are developmentally delayed and multiply disabled. Nestled in the heart of the Berkshire Hills, the attractive and carefully-designed campus also houses several cheerful residences and a Learning Center equipped with state-of-the-art teaching aids. The program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of pre-cognitive, cognitive, pre-vocational and independent living skills. There is an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.



At Berkshire Meadows we believe that all children, no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

For further information, please contact: Ms. Gail Charpentier, Berkshire Meadows,
249 North Plain Road, Housatonic, MA 01236 (413) 528-2523

== Schools, Camps & Residences Directory ==

Arizona

Hacienda de los Angeles
1402 E. So. Mountain Ave.
Phoenix, AZ 85040
(602) 243-4231

Quality care in a state-of-the-art medically orientated, yet home-like facility for chronically ill infants, children and young adults.
See ad page 49

California

Frostig School
971 N. Altadena Drive
Pasadena, CA 91107
(818) 791-1255

Private non-profit school for learning disabled children without serious emotional problems. The school provides an interdisciplinary education for children 6 through 18 years of age. Nurturing, whole child oriented, with strong enrichment opportunities.

Southern California College of Optometry
2575 Yorba Linda Blvd.
Fullerton, CA 92631
(714) 449-7432

Comprehensive diagnostic and therapeutic vision care for visual impaired, exceptional and learning disabled children and adults.

Connecticut

Chapel Haven, Inc.
1040 Whalley Ave.
New Haven, CT 06515
(203) 397-1714

Residential and Independent Living Programs for young adults with learning disabilities, mild retardation and neurologic impairments.

Florida

The Duvall Home
3395 Grand Ave., P.O. Box 36
Glenwood, FL 32722
(904) 734-2874

A Private, non-profit residential facility providing a warm and loving atmosphere for ambulatory and non-ambulatory mentally disabled of all ages. 24-hr nursing care. Lovely 24-acre rural campus. Recreational & training activities and respite care available.

Eckerd Family Youth Alternatives, Inc.

P.O. Box 7450
Clearwater, FL 34618
(813) 461-2990

Outdoor residential programs for children and adolescents with emotional problems. Ages 10-16. Accredited. Private/insurance accepted.

Ralph J. Baudhuin School of Nova University
3375 SW 75th Avenue
Ft. Lauderdale, FL 33314
(305) 475-7324

A private non-profit day school for children with learning disabilities, attention deficit disorders, speech and language impairments, communication disorders and hearing impairments. Serves ages birth to eighth grade.

Sunrise Rehabilitation Hospital, Florida

(800) 648-9111/(800) 634-9111
Pediatric/adolescent program offering specialized rehab. care following accidents or acute illness. Ventilator patients and coma recovery.

Georgia

Agape Village
Church of the Exceptional
3711 Agape Village Road
Macon, GA 31210-4098
(912) 471-3700

Providing mentally disabled persons with a pleasant, sheltered place to live, work, worship & play as independently as possible.

Annadale Village
3500 Annadale Lane, Box 7
Suwanee, GA 30174
(404) 945-8381

Private, non-profit community for adults with developmental disabilities. Residential and day/evening programs & services. Features such benefits as paid job training, arts activities, therapeutic recreation and case management all surrounded by 125 acres of woodlands.

Illinois

Bartlett Learning Center
801 W. Bartlett Rd.
Bartlett, IL 60103
(708) 289-4221

For children and young people, 3-21 years, with mental handicaps (incl. TMH & EMH), learning disabilities and/or behavior disorders.
See ad page 57

Brehm Preparatory School
1245 East Grand Ave.
Carbondale, IL 62901
(618) 457-0371

Residential school designed to meet the academic, social and emotional requirements of adolescents (age 12-21) with learning disabilities.
See ad page

Kansas

Hartspring Assessment and Treatment Center
2400 Jardine Drive
Wichita, KS 67219-4699
(800) 835-1043

Short-term, extended and summer assessments for multiply disabled children ages 3 through 21. Specializing in speech and language disorders. Helping special-needs children reach their potential for more than 50 years.

Lakemary Center
100 Lakemary Drive
P.O. Box 449
Paola, KS 66071
(912) 294-4361

Educational, residential and vocational services to children and adults with a primary diagnosis of mental retardation. Serving all 50 states.
See ad page

Kentucky

The Stewart Home School
Box 20
Frankfort KY 40601
(502) 875-4664

Progressive education, home environment for mentally handicapped children and adults. Multiple recreation and activities. Year round program. Est. 1893. Call or write for brochure.

Maryland

The Ivy Mount School
11614 Seven Locks Road
Rockville, MD 20854
(301) 469-0223

Day program. Birth to 15 with multiple disabilities. All therapies. Expressive arts, physical education, computers, augmentive communication.

Massachusetts

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 01236
(413) 528-2523

For children who are severely retarded, multiply disabled. Private, non-profit residential school located in the Berkshires.

Cardinal Cushing School and Training Center
400 Washington Street
Hanover, MA 02333
(617) 826-5371

Provides academic, residential and vocational prog. for all levels of developmentally delayed students to help them lead fulfilling, productive lives. Program includes Prader-Willi Syndrome and international students. Ages 6-22.

Crystal Springs School
38 Narrows Rd. Box 372
(508) 644-3101, Ext. 328
Assonet, MA 02702
Established in 1953, Crystal Springs offers licensed home-like residences; and approved private school; full rehab. program; and 24-hour licensed nursing coverage designed to meet the needs of medically fragile, multi-handicapped children and young adults. birth-22 yrs.

Evergreen Center
345 Fortune Blvd.
Milford, MA 01757
(508) 478-5597

A licensed, private, non-profit residential school. Students live in community setting, learning basic skills in classroom, community and residence.

The Kolburne School, Inc.
Southfield Road
New Marlborough, MA 01230
(413) 229-8787

A coed Residential Treatment Ctr. providing a safe, structured, warm, therapeutic environment for students ages 8-24. JCAHO accredited.

The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities. 12 mo. day/residential. See ad page

League School of Boston, Inc.
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260/Fax (617) 964-3264
Day & residential school for children & young adults 3-22 years of age with Autism & related developmental disabilities. Vocational program/on-site job training. School utilizes psycho-educational approach. 20-acre adult farmstead. See ads pages

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Day/residential school for children with develop. disabilities, behavior disorders age 3-22. Integrated preschool, inclusion svcs. staff intensive prog., functional activity based curr., supported employment in modern school and group homes.

Riverview School
551 Route 6A, East Sandwich
Cape Cod, MA 0002537
(508) 888-0489

For high school students (12-19) who are learning disabled but also marginally impaired intellectually. Located on Cape Cod. Riverview offers a modified curriculum which provides a high school diploma. Post graduate programs are also available.

South Shore Center for Brain Injured Children, Inc.
Braintree High School
128 Town Street
Braintree, MA 02184
(617) 848-0285

Day School. 12 month program for severely, multiply disabled children, ages 3-12. Education, therapies, nursing skills available. 1 to 1 ratio as often as possible.

Missouri

Missouri School for the Blind
3815 Magnolia Avenue
St. Louis, MO 63110
(314) 776-4320 or
(800) 622-5MSB
Statewide resource center of excellence providing quality services to blind and visually impaired individuals ages 5-21 and their families at its centerbase and throughout the state

Montana

Yellowstone Education Center
1732 So. 72nd Street W.
Billings, MT 59106-3599
(800) 726-6755
Serves emotionally disturbed students ages 6-18 on a beautiful 400 acre campus in Billings, MT. Residential and day programs with psycho-educational, neuro-developmental and other educational evaluations offered. SCAHO accredited and state licensed.

New Hampshire

Crotched Mountain Rehabilitation Center & School
1 Verney Drive
Greenfield, NH 03047
(603) 547-3311
Comprehensive special education preparatory school grades K-12 for multiply disabled students. Open campus; skilled nursing unit; family style group home campus; full range of clinical, therapeutic, medical and dental services, rehabilitation and therapy programs. See ad page

New Jersey

Bancroft, Inc.
Hopkins Lane
Haddonfield, NJ 08033
(609) 429-0010
Leading private, non-profit agency with 110 years experience. Educational, vocational, residential and therapeutic services for children and adults with developmental disabilities and brain injuries. State-of-the-art technology with emphasis on community living.

Githens Center (Burlington County Cerebral Palsy Assoc.)
Cedar Street
Mount Holly, NJ 08060
(609) 261-1667
Education program with an extended school year for children 3-13 with multiple disabilities, including cerebral palsy and other physical disabilities. Intensive therapies available. Day care, respite, recreation, medical and adult services.

New York

Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840
A co-ed res. camp for learning disabled, ADD, neurologically impaired and mild-moderate MR located in the Catskill Mts. of NY state.

The Developmental School
380 Washington Avenue
Roosevelt, NY 11575
(516) 378-2000, Ext. 290 or 260
Children from birth to age 21 with cerebral palsy and other mild to severe disabilities. Comprehensive on-site therapy, treatment and support services. Respite, leisure and head injury services provided as well.

New York University - Para-Educator Center
One Washington Place
New York, NY 10003
(212) 998-5800
Two year post-high school program for severely learning disabled young adults. Courses & supervised job training in human services, while emphasizing independent living skills. Graduates qualified to work with infants, toddlers, young children or senior citizens.

North Carolina

Eckerd Family Youth Alternatives, Inc.
388 Nine Mile Road
Newport, NC 28570
(800) 554-4357
Outdoor residential programs for children/adolescents with emotional problems. Ages 10-16. Accredited. Private/insurance accepted.

North Dakota

Ann Carlsen School
301 Seventh Ave., NW
Jamestown, ND 58401
Committed to providing individualized education and rehabilitation, through diagnostic evaluation and therapy.

Ohio

Cleveland Sight Center/Highbrook Camp
1909 E. 101st Street
Cleveland, OH 44106
(216) 791-8118
On site/in home program for visually impaired preschoolers. Resid. summer camp for visually impaired, deaf-blind, multiple disabled, all ages.

St. John's Villa
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615
(216) 627-9789
Catholic, non-profit residential community (N. Eastern Ohio) provides caring environment for adult residents toward self-acceptance/respect.

Pennsylvania

The Devereux Foundation
(800) 345-1292, Ext. 3045
(215) 964-3045
FAX (215) 971-4600
Residential, day and community-based treatment centers nationwide. Comprehensive services to individuals of all ages with emotional disturbances, developmental disabilities, mental retardation, dual diagnosis, autism, and post-head trauma.

Pennsylvania (cont'd)

Erie Infants and Youth Home, Inc.

226 East 27th Street
Erie, PA 16504
(814) 454-1534

Community-based residential program serving children and young adults with developmental disabilities. 24 hours a day skilled nursing and direct case services. P.T., O.T., speech, recreation-camp, nutrition behavior management.

Elwyn, Inc.

111 Elwyn Road
Elwyn, PA 19063-4699
(215) 891-2040/(800) 345-8111

Caring for over 10,000 children & adults. Offers transitional services. 24 hr. health care, vocational training & placement, modern, homelike residence. *see ad page*

H.M.S. School for Children with CP

4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566

Residential/day school program for children 2-21 who are severely physically disabled by CP. Integrated therapies. Assistive tech. *see ad page*

Keystone City Residence

406 N. Washington Avenue
Scranton, PA 18503
(717) 346-7561 Mr. Fleese
Community homes, urban & rural, located in NE, PA, Pocono Mtns., NJ. Avail. to child & adults with dev. dis. Summer camp with arts feature, voc. and work placement and full prof. & support services. Prader-Willi program. Reasonable fees & highly regarded program. Fully licensed.

Martha Lloyd Community Services

190 West Main Street
Troy, PA 16947
(717) 297-2185
For persons with Prader-Willi Syndrome. Manages the unique nutritional/dietary needs and social and emotional challenges common to this disorder. Academic and vocational training, plus outstanding social and recreational opportunities. *See ad page*

Pathfinder Village

Box 32-A
Edmeston, NY 13335
(607) 965-8377

Opportunities abound in this colonial style village that provides quality life experience for children and adults with Down Syndrome.

Rhode Island

Behavior Research Institute

240 Laban Street
Providence, RI 02909
(800) 231-5405

Drug-free behavioral residential program for autistic/MR. No rejections or expulsions. Success with the most difficult cases. 3 to adult.

The Groden Center, Inc.

86 Mount Hope Avenue
Providence, RI 02906
(401) 274-6310

Education & treatment for children & young adults w/autism & other developmental disabilities. Vocational programs; positive self-control techniques.

South Dakota

Crippled Children's Hospital and School

2501 W. 26th Street
Sioux Falls, SD 57105-2498
(605) 336-1840/(800) 584-9294
A private, non-profit facility with outreach, outpatient, day school and residential services for children from birth through age 21 who have disabilities or chronic illnesses. Our multi-disciplinary teams provide family-centered services based on each child's needs.

Crippled Children's Hospital and School Outreach

510 N. Cambell
Rapid City, SD 57701
(605) 342-4412/(800) 584-9298
Branch of Crippled Children's Hospital and School providing outreach and outpatient services for children through 21 who have disabilities or chronic illnesses. Our multi-disciplinary teams provide family-centered services based on each child's needs.

Tennessee

The King's Daughters' School

412 West Ninth Street
Columbia, TN 38401
(615) 388-3810

Residential school for students 5-21 with mental retardation. Low pupil/teacher ratio. Downtown campus, new facilities. 12 mo. program.

Tall Pine Camp

Rt. 2, Box 194-A
Tellico Plains, TN 37385
(615) 261-2329

Co-ed mountain camping for children and adults with MR. Activities based on individual abilities. 2,3,6 week sessions.

Virginia

Faith Mission Home

HCR 1 Box 114
Free Union, VA 22940
(804) 985-2294

Res. care and training center for ambulatory MR or brain-injured children and young adults located in Blue Ridge Mountains.

Northern Virginia

Developmental Preschool

888 Dolley Madison Blvd.
McLean, VA 22101
(703) 356-2833

A private, non-profit preschool for speech and language delayed children. Individual speech therapy included.

Wisconsin

Bethesda Lutheran Homes & Services

700 Hoffman Drive
Watertown, WI 53094
(800) 369-INFO

Providing residence & varied services for disabled individuals or clients. Call for more information on specific religious services.

Chileada Habilitation Institute

1020 Mississippi Street
La Crosse, WI 54601
(608) 782-6480/FAX (608) 782-6481

Residential treatment for children with severe mental & physical disabilities, closed head injuries & challenging behaviors. *See ad page*

St. Coletta School

W4955 Highway 18
Jefferson, WI 53549
(414) 674-4330

Year-round res. program in academic instruction and prevocational training for MR/DD. Adult res. facility w/work opportunities for aging MR/DD.

Treatments for Attention Deficit Hyperactivity Disorder

Excerpted with the kind permission of Research Press. To order *Attention Deficit Hyperactivity Disorder*, send \$11.95 plus \$4 shipping and handling to: Research Press, 2612 N. Mattis Avenue, Champaign, IL 61821 or call (217) 352-3273.

Editor's note: "The double-blind, placebo-controlled study" described in this excerpt for use of psychostimulant medication is a clinical method that can usually be used to evaluate any medication designed to change behavior.

Once a child has been appropriately diagnosed as possessing attention deficit hyperactivity disorder (ADHD), one or more treatments may be attempted. Although most research suggests that a combination of treatments is most effective, it is important to understand that no treatment approach is thought to "cure" ADHD. Rather, with the right combination of treatments, the frequency, intensity and duration of problems associated with ADHD may be reduced.

What treatments are available to help the child with ADHD?

The most common treatment for ADHD is, and has been for some time, psychostimulant medication. There are many types of such medication; the most commonly used is methylphenidate, often referred to by one of its trade names—Ritalin. Other psychostimulant medications include d-amphetamine (or Dexedrine) and

pemoline (or Cylert). Such medication is thought to exert its beneficial effects by stimulating the brain areas that enable a child to sustain attention, delay impulsive responses, control motor activity and plan behavior.

Is it true that psychostimulant medications are mind-altering drugs?

The answer is yes, but only in terms of activating the attention, body movement, organization, motivation and planning ability centers of the brain. Psychostimulants are definitely not mind-altering drugs in terms of changing one's personality or one's perception of reality. In other words, although psychostimulant medications may help a child to better focus his attention, delay impulsive responding and organize himself in a more efficient manner, they do not cause him to experience distortions of reality.

If these medications are stimulants, why do they seem to calm children with ADHD?

Although the medications frequently given to children with ADHD are psychostimulants, they do not increase the child's activity level. Indeed, because these medications appear to have a calming effect on such children, some have called their effects paradoxical. However, in reality there is nothing paradoxical about the effects of psychostimulants on children with ADHD. This becomes clear when one recognizes that the psychostimulants primari-

ly affect the areas of the brain that support focused attention, planning and organization. When the child with ADHD becomes better able to focus her attention and plan her behavior, she will appear less distractible, less impulsive and less disorganized. All of these changes will result in a decreased activity level—after all, if she is glancing around the room less, is better able to resist impulses to get out of her seat and is more organized in her efforts, she will be less physically active than if she is looking around, moving about and behaving randomly. In fact, recent studies have shown that children without ADHD are affected in exactly the same way by psychostimulants as are children with ADHD. That is, children without ADHD are also better able to focus attention and organize behavior when on small doses of psychostimulants.



Are you saying that my child will be fine once he takes the medication?

The answer is maybe. It appears that the psychostimulant medications are helpful for temporary control of ADHD symptoms but may not be helpful in the long run. In other words, psychostimulant medication seems to be effective for the immediate management of children with ADHD, but it may not be helpful in preventing future social and academic difficulties. One reason that the medication may not enhance future adjustment is that taking medication does not teach a child any skills; it only helps him to pay attention, as well as to control and plan behavior.

How do I know whether medication is the right treatment for my child?

After your child has received a comprehensive evaluation and been diagnosed as having ADHD, she may be referred to a physician to determine the appropriateness of the use of psychostimulant medication. Remember, only a physician, such as your child's pediatrician, can decide whether your child should be placed on psychostimulant medication. If so, the physician will ultimately be responsible for managing the medication treatment. Medication is generally not prescribed for children under the age of 6, as its safety and effectiveness for such young children have not been well established. If medication is recommended, the physician should first give it on a trial basis to determine whether it is helpful and, if so, what the proper dosage is.

How exactly does the physician conduct this trial?

One popular means for conducting this trial is a double-blind, placebo-controlled study. By using this method, a physician can evaluate impartially whether psychostimulant medication is an appropriate treatment for a child with ADHD. The procedures used in this kind of study are somewhat complicated and should be directed by the physician pre-

scribing the medication, often with the aid of a psychologist. Most physicians typically do not perform double-blind, placebo-controlled studies because they are time consuming and require specialized knowledge. For this reason it is often helpful to have a knowledgeable psychologist involved—to help ease the time demands on the physician and to help coordinate and implement the procedures.

In a double-blind, placebo-controlled study the child with ADHD is given the psychostimulant medication on some days, whereas on other days she receives a placebo, a pill containing no medication at all. The child, her parents and her teachers will not know on a given day whether the medication or the placebo is being taken; only the physician (and psychologist, if one is involved) will have this information. Both the parents and the teachers then make daily ratings of the child's behavior. In addition to these behavioral ratings, certain psychological tests, which measure attention span and impulsivity, can be used to monitor the effectiveness of the medication. If the medication is helpful, the daily behavior ratings and the psychological tests will show improvement primarily on the days the child takes the psychostimulant medication, as opposed to the placebo. If the medication is not helping the child, either there will be no improvement regardless of the type of pill she takes or there will be an equal amount of improvement when she takes the medication and when she takes the placebo. The physician may also use different medication dosages in a double-blind fashion to determine the most appropriate dosage for a particular child. A double-blind, placebo-controlled study is useful in evaluating the effects of psychostimulant medications because psychostimulants show immediate effects, unlike certain other medications that show their effects only after some time has elapsed.

Can medication make children "crazy" when they are older?

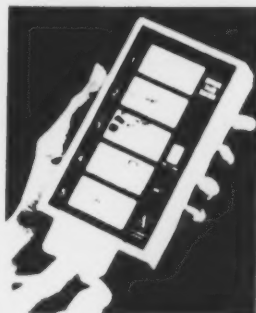
There has been much recent debate about whether medications such as

Ritalin cause future emotional or behavioral difficulties. Research has not substantiated such harmful future effects, although harmful effects have been reported in some cases when medication was administered in excessive doses over long periods or when medication was prescribed to children who should not have been receiving it. For instance, highly anxious children or those with muscular ties may not be particularly good candidates: Psychostimulant medication has been shown to be less useful with such children, and in some cases it may even aggravate their anxiety or muscular ties. Some also believe that children with seizure disorders or epilepsy should not be prescribed psychostimulants because such medications may increase seizure activity. Another indicator against the use of psychostimulant medication is the presence of certain mental disorders such as thought disturbances. In addition, psychostimulants can interfere with the activity of other medications; other medications, such as antihistamines, can also alter the effectiveness of psychostimulants. Be sure that your child's physician carefully rules out these indicators before prescribing any medication.

Should my child's medication treatment be monitored regularly?

Yes. The physician should be kept informed of any side effects, as well as observable benefits, that you think your child is experiencing. In addition to your regular reports, the physician can use a double-blind, placebo-controlled study to monitor the effects of the medication about every 12 months. Such re-evaluations are necessary because a child's attentional and self-control abilities may improve over time. Such improvement may lessen the need for continued psychostimulant treatment. Also, as children mature, they gain weight. Because the effects of psychostimulants are, to some extent, influenced by body weight, adjustments in the medication dosage may be needed as your child becomes heavier. ■

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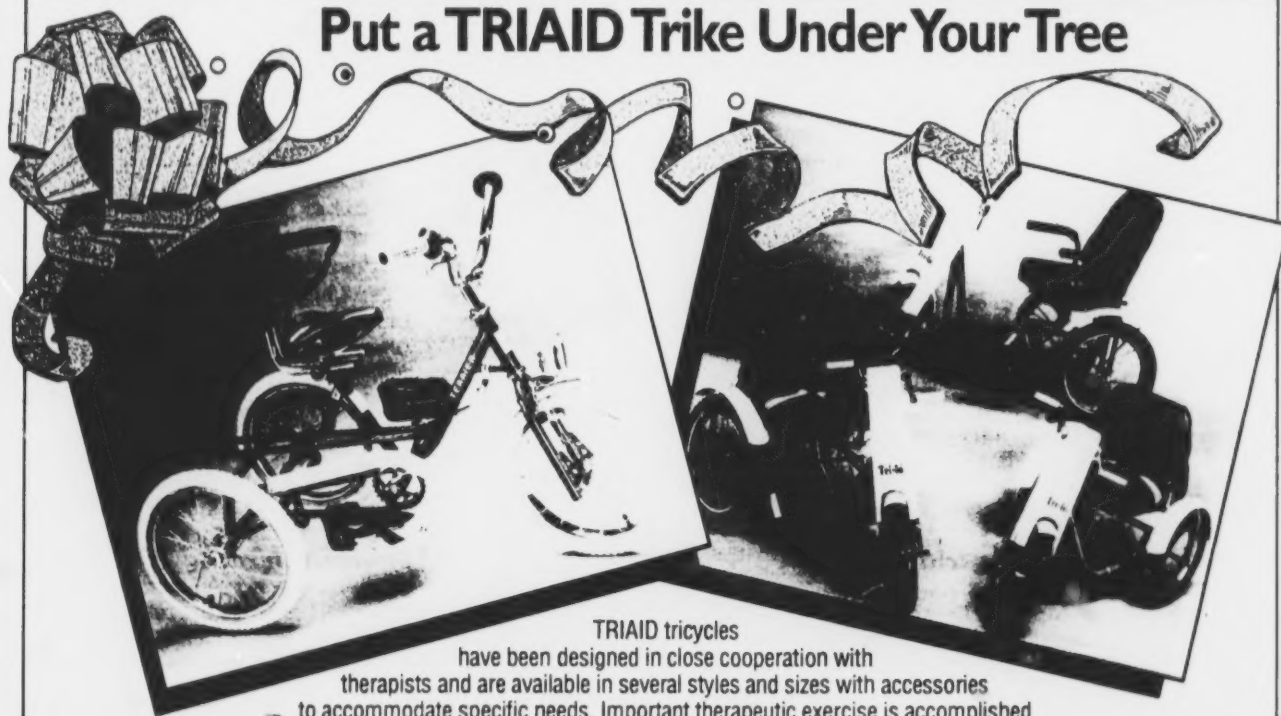
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Residential Placement: Coping with Separation

Karen Cord Taylor

Although G.S. had multiple disabilities, for 16 years his mother was able to care for him at home. His family lived in an accessible house in Massachusetts and had help from a number of aides. He was attending a wonderful day school where he was learning a surprising range of skills.

After his parents divorced, G.'s mother moved into a smaller house in a neighborhood that was inconveniently located for the family aides who had been with G. for many years. G.'s father, who loves him and continued to participate in his care, first suggested that it was time to find a residential setting for G. When G. was 16 years old, he went to live at a residential school in the same state. The move was difficult for his mother.

Never Easy

"Placing him was a traumatic experience," says Ms. S. "I dreaded having to do it."

Ms. S. isn't alone in her trauma. Most parents find it difficult to face the idea of handing over care of a child with disabilities to others.

"It's never easy to reach this kind of decision when you have a child with a severely disabling condition," says Valerie Pekar, senior case advocate and intake supervisor at Advocates for Children, a Long Island, New York, agency that assists families in finding the right services for children with disabilities.

When?

Many parents come to a turning point when they decide to seek residential care for a child with disabilities.

"We'd prefer that kids would be a success at home because having to be away from home is a drawback," says the director of a mid-western residential school for 12 to 22-year-olds with learning disabilities and/or attention deficit disorders. "But sometimes living at home can be more of a drawback." The teens who come to the mid-western school may be subject to enormous stress at home, the director explains, facing failure every day in the classroom and being isolated from peers who are intolerant of their disabilities.

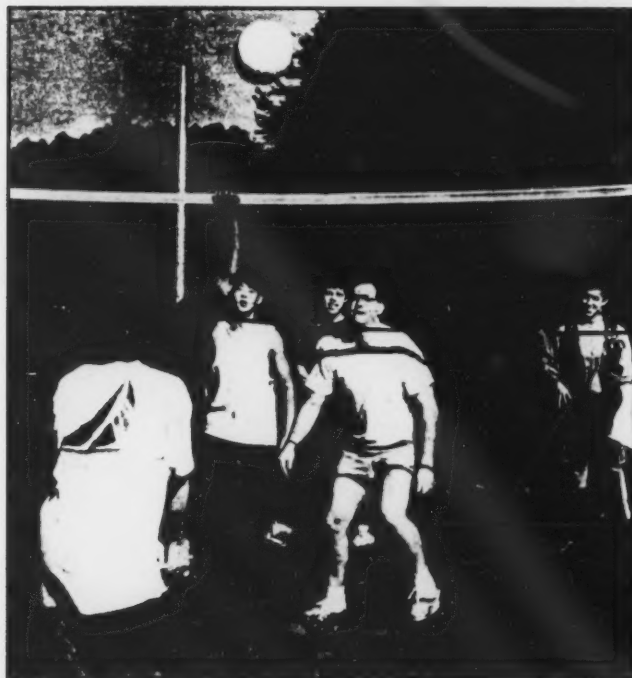
"When students come to live here, they find friends for the first time," says the director. "They learn how to be successful in a classroom. They get support and their parents



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get support from other parents. The stress is relieved for both the student and the family."

Some parents are willing and able to take care of a child with disabilities but have no educational settings nearby that can provide services. This is especially true for children with severe and/or rare disabilities. "The way things are, parents sometimes have no option but to place a child," says Pekar.

Also, the placement of a child may bring up parents' concerns about their own mortality. "There's always the lurking knowledge that as parents grow older and less capable, they can't care for their child as well," says Dr. T., a psychiatrist and the father of W., who has multiple disabilities. The T.'s sought residential care for their son when his older siblings, who had shared in his care, left home for college.

No matter what the disabling condition, the early adolescent years are a typical time when some families begin to consider residential placement.

"There comes a time when the level of demand and the degree of burden grows too much for a family," says the director of a western Massachusetts-based residential school for children with severe and multiple disabilities. "When a child with disabilities is small and young, it can make a lot of sense for him or her to live with a loving family," she observes. "But puberty happens. Adulthood is on the horizon. This child needs to grow up optimizing his or her skills in the same way all children do."

The decision is sometimes hastened by the realization of how much time and attention the child with disabilities is taking away from the other children in a family, although most parents believe their other children have developed special sensitivities and insights because of their sibling with a disability.

Placement Process

Although the reasons for seeking residential placement can be compelling, that doesn't mean it's easy to accomplish. First, there is the loneliness in going through the process. Residential placement for children with disabilities is not common. Estimates are that fewer than 0.9 percent of America's school-age population, or about 36,000 children with disabilities, is in residential schools. Pekar says that out of the over 350 children that her agency deals with each year, only 2 or 3 families seek residential care. It is usually those children with the most disabling physical, behavioral or intellectual conditions who are the candidates for residential placement.

The rarity of residential placement means there are fewer schools from which to choose, fewer parents in similar situations from whom to get advice and less experience on the part of child advocates and school officials in helping parents to find and evaluate residential facilities. A school that parents like that has the right services for a particular child may be in another state or even in another region of the country.

Moreover, parents may feel guilty. "It was hard to admit I wasn't going to take care of him," says Ms. S., who believes she would never have made the decision had her

former husband not encouraged her.

Although guilt may make parents reluctant to consider residential placement, it is often over-played by social workers and advisors. Dr. T. believes. "Families feel guilt," he says. "But feelings of grief and fear are stronger." Dr. T. believes that when a family places a child with disabilities in a residential setting, the family experiences emotions similar to any family in which a child leaves home. "It is similar to the empty nest syndrome, but it has an extra poignancy," he says. "It involves the same grief or mourning, but there is also a pervasive sadness that this situation exists and this child of ours is limited as he or she is and always will be."

Parents may also fear that the child won't be taken care of as well as he or she has been at home. If the child is severely and multiply disabled, will the caretakers understand the child's way of communicating? Will they know the child is hungry, uncomfortable or sad? Will they be able to comfort him or her successfully? If my child is dependent on me, will any one else do as a good a job as I can?

Fears can also stem from the stigma that surfaced as the de-institutionalization trend took hold. "I thought he could die—if not physically, then emotionally," says Ms. S. "From the time he was first diagnosed, I couldn't conceive of an institution." It seemed degrading and diminishing."

Benefits

The benefits can temper the concerns, if not alleviate them. Residential placement may provide the needed structure and/or special therapies a family naturally cannot. "Mothers and fathers have to go to work, they have dinner to make, they get tired and they need to spend time with their other children," explains the director of the school for children with multiple and severe disabilities. "Our staff doesn't have to do any of these things. They come in fresh, ready to start the day."

Another advantage for some children who are physically fragile is the reduced need for transportation. In many communities, transportation for children with special needs is often poorly supervised, with bus drivers and/or attendants who have little training. Parents worry about their child having a seizure, or becoming confused or even injured. The most appropriate day placement can be an hour's ride away, especially when there are several children to pick up. The travel time could be better spent in instructional or social time. For children and their parents the elimination of transportation can be an enormous relief.

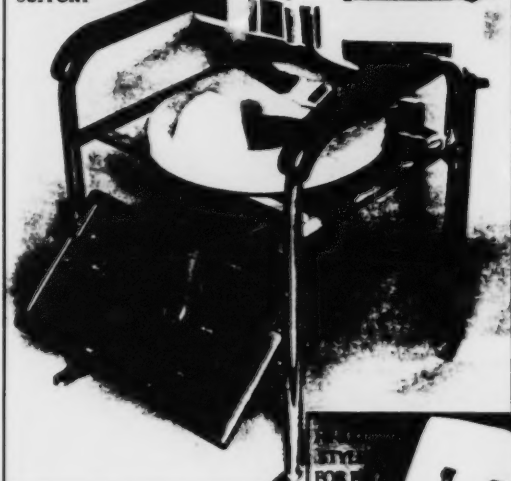
Some children progress faster with the constant stimulation and instruction that can go on in a residential setting. "Our staff can give the child round-the-clock, consistent training with no distractions," says one residential school director. "If a child needs behavior modification we can do it here. I think it's inhuman to expect families to do this. It's unnatural in a family where life is more free-flowing."

For some students at the mid-western school for children with learning disabilities, the major benefit from living there is a happier child, says the director. He sees the constant attention and reinforcement as factors which help to increase the students' independence. "They learn to take

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control of their own learning. They learn to identify the sources of their anxiety so they can prepare for difficult situations," he says.

There are benefits for parents, too. For parents whose children have low-incidence disabilities, and that is a significant part of the residential population, the new setting can introduce them for the first time to other parents who have gone through experiences similar to their own. That support, say school directors, proves invaluable to some parents who have been going at it alone for many years.

A Long Search

Most parents who decide their child would best be served in a residential setting say the process took a very long time. Ms. S. says removing her son from his day school, where she had grown so attached to his teachers and caregivers, was heart-breaking. She took a year to find the right residential setting. It was public school officials who eventually steered her to an appropriate school.

The T. family, although more resolved about placement than Ms. S., nevertheless took longer than she did to find the right residential setting. Mrs. T. screened dozens of places and then both parents went to look at nearly 20 placements in several states over a couple of years. "Places that might have dealt well with his cerebral palsy might not have been as well equipped to treat his mental retardation," says Mrs. T. "We wanted to find a place where he would be understood and worked with compassionately and skillfully."

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While the T.'s had basic standards about cleanliness and attractiveness, they were able to make more subtle distinctions as the process went on. They learned to avoid places operating on what Dr. T. calls a "gung-ho" ideology. "We wanted people who would see our child and not the ideology," he explains. Dr. T. says they made one visit to a place with a good reputation, but he began to feel ill and had to leave. The place was clean, but the atmosphere seemed sterile and barren. If it was oppressive for him, he reasoned, it would also be oppressive for his son.

Checking Up

Proof that placement has been best for the child is essential to coming to terms with the decision. The school itself must make it easy for parents to evaluate their child's progress and satisfaction.

At the most basic level, schools need to maintain an open door policy that welcomes parents at any time to talk to any staff member. The parents we talked to said their visits averaged about once a month. With more able students who can talk on the phone the visits might be less often, just as they would be with any child. Next, the school should provide regular written reports of the student's progress and activities. Finally, school policy should include contacting parents when any change in treatment or medication is recommended.

Parents also rely on their children's attitudes for confirmation that residential placement is best. With teens at the mid-western school for children with learning disabilities, a change for the better is often apparent after a few months, says the director. Students who once were depressed, withdrawn or out of control can change those behaviors—solid evidence for parents that they made the right decision.

But proof can be more difficult to come by in children who lack standard communication methods. "Behavior changes over time," says Ms. S., "and it's hard to attribute it to a residential setting." She says her son regressed somewhat after his placement away from home. But she characterizes his memory and connectedness as "pretty wonderful," proof to her that the residential setting is succeeding.

Parents often notice tell-tale signs that their child is happy or unhappy—signs which school staff may not immediately recognize. To assure themselves of W.'s satisfaction, the T.'s always check their son's hands because he bites the backs of his hands when he's upset.

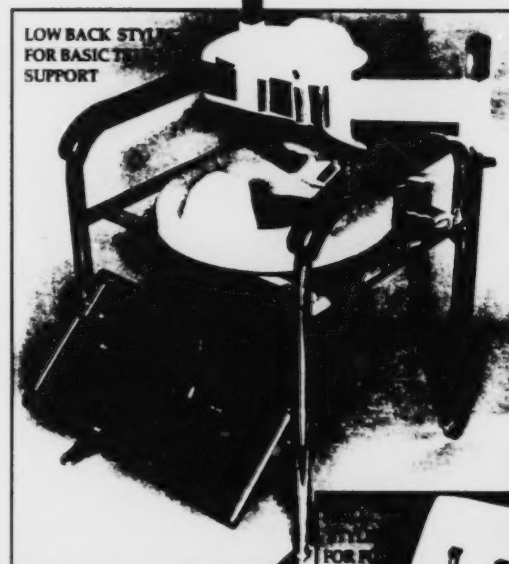
Is It Worth It?

Inevitably after the child has adjusted to the residential setting and the family has coped with the loss of a family member away from home, there is a feeling of release and relief. "In retrospect," says Dr. T., "caring for W. was a real burden on the other kids in the family. At the same time his presence was clearly a gift and ultimately a life work for some of our other children." W.'s two sisters have both gone into careers related to people with disabilities.

But there are ups and downs. "It's not all roses," says Dr. T. "Sometimes the staff changes and some staff are naturally better than others. There can be temporary setbacks.

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And with some children temporarily can be a long time." But, over time, W. has learned skills no one ever predicted he would learn and he seems happy, says his father.

G. has also had his ups and downs—and so has his mother. After moving through the initial period of loss, Ms. S. completed a degree in social work and wrote a cookbook. She believes G. lost some functioning but gained in other ways. "For all the loss," says Ms. S., "my life has gained and G. is extremely happy. He laughs a lot." ■

Karen Cord Taylor is the author of Blue Laws, Brahmins and the Breakdown Lanes: An Alphabetical Guide to Boston and Bostonians, and co-author of The Lady Architects, as well as more than 100 newspaper and magazine articles. She also runs a newsletter publication business. Before she became a writer, Taylor earned a master's degree in special education and taught children with learning disabilities.

Special thanks to Richard Collins, director of Brehm Preparatory School, Carbondale, Illinois, and to Gail Charpentier, executive director of Berkshire Meadows, Housatonic, Massachusetts, for providing information for this article.

What to look for in a residential setting

The parents, placement professionals and school directors we talked to made several recommendations about evaluating potential residential settings.

- Select a school based on the services it can provide your child, not solely on its proximity to your home.
- Look for schools with an 'open door' policy. Parents should be welcome at any time and have easy access to all the professionals taking care of their child.
- Consider only schools where the child's needs are paramount. Avoid schools that rely on a rigid ideology or method, where you or your child might be made to feel guilty if you don't completely conform to the school's expectations.
- Look only for schools that successfully promote and support active parent groups. Other parents can provide valuable support and advice.
- Look for a school that supplies you with several parents to contact while you are investigating. Other parents will usually be candid about their experiences.

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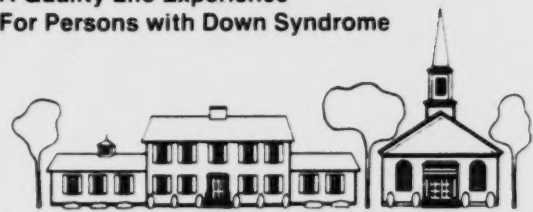
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Effective Parent Advocacy: How to Take Charge

Helen Rader & Jenifer Simpson

This article has been adapted from *Advocacy—Taking Charge: How To Do It* by Helen Rader and Jenifer Simpson. Published by United Cerebral Palsy Associations © July 1992

According to Webster's dictionary, advocacy is *active support for a cause*. To advocate is *to speak in favor of or to defend (someone)*. For parents of children with disabilities, it is speaking up on behalf of your child to ensure that his or her needs and rights are met. It is often confronting authority. Sometimes, it is simply getting out there and fighting for your child's rights. Here are some tips that will help you become your child's best advocate.

On Behalf of Your Child

Believe in your child. Believing in your child is essential. No doctor, therapist or teacher—no one—knows your child better than you do. You have lived with your child with a disability longer and more intimately than anyone else. Only you have the long perspective—the big picture. Trust that knowledge.

Believe and trust in your own insight and intuition. Believing in your intuition is being able to trust yourself and those feelings you have. A hunch is usually a sign. Follow your hunches.

Remember that information is power. Educating yourself is critical. You do not have to become a walking encyclopedia about disability law. But it is very important to learn what your child's rights are before you can fight for them. There are many sources of education and support in your state. There are advocates in your state—at United Cerebral Palsy affiliates, the Protection and Advocacy agency and at parent training centers. They are your allies and will prepare and support you. The more skills and information you learn the better you can advocate.

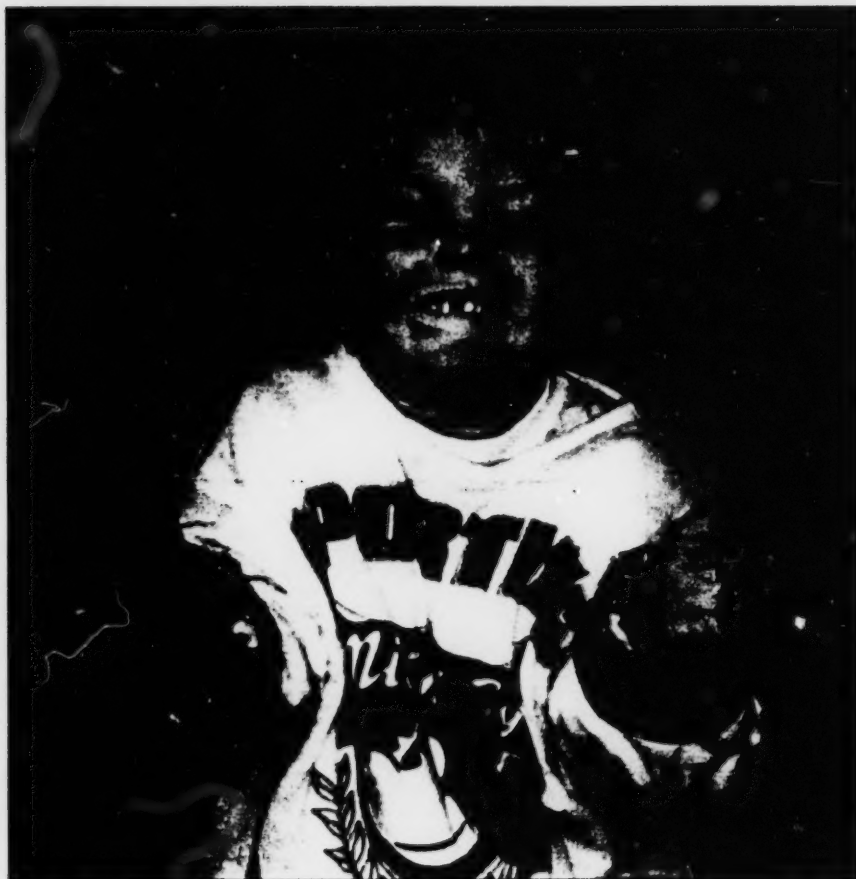
Be a change agent. The squeaky wheel gets greased. You can do it!

Advocacy Tips:

- **Documentation.** Keep a notebook. Always write down facts and keep a "paper trail." There are two different kinds of facts—objective and subjective.

Objective facts are the name, telephone number and





Above: Will Reisner

Previous Page: Josbua Chartienitz and his mom, Jenifer Simpson, at the Washington Monument on the day P.L. 101-336 (ADA) was signed.

title or position of the person you talk to. Don't be afraid to ask. Say: *Just a minute, please. I need your name and title. I'm writing this down.*

Facts are lists of questions you ask and answers you receive. Put quotes around answers. Ask the person to repeat themselves or say: *I heard you say that you do not think Jesse can be in your day care center because he has a wheelchair. Is that what you said?* Write it down. It is helpful to say that you are writing the responses into a notebook.

If you get an answer that you don't agree with, don't understand or you know is wrong, say so. Always ask for the statement to be sent to you in writing. Say: *Please send me a copy of that in writing.* Make this request when you are talking with educators, health care professionals, insurance companies, Medicaid, community agencies, hospitals, landlords, restaurant owners and others.

Keep a file folder, box or drawer for the written replies and paperwork you will receive. If you have time, organize it either chronologically or by

subject.

Subjective facts are your personal thoughts and feelings about either a person or an event that occurred. Did the person act friendly? Ignorant? Were they willing to talk with you? Were they evasive? Just jot down a couple of words or sentences to remind you what kind of conversation you had.

Remember to keep your notes on facts and opinions in one place—either on a computer disk or in an organized notebook. This is a quick and easy way to make sure that your notes are not here and there, but easy to find. Over the years, you will see why having your notes together is a time saver.

Always date your notes.

• **Phone calls.** Record phone conversations in the notebook. Include the date and time of the call, along with the name, title and telephone number of the person you spoke with. Before placing the call, write down the questions that you will ask, leaving space for the answers. Realize that a phone conversation can be forgotten—or denied.

Try to talk to the 'power' person or the person who has the critical information you want. It may take a while to get to the person who has the authority to state policy, so persist in trying to reach a person of authority. Call an agency and say:

Who is the person responsible for putting together the IEP team?

May I speak with the policy expert on the Medicaid state plan?

Who determines the transportation schedule for school buses?

Who is the expert on assistive technology funding in our school district?

If you don't know what an IEP is or whether your child is eligible for Medicaid, that is the call you need to make tomorrow.

When you make a call, try to leave pleading and begging behind. Be as direct as you can with your initial request. Simply say:

Hello. This is Jane Doe calling for Mr. Sampson. Period.

My son can't see very well and has cerebral palsy. What are the steps I must take to get him enrolled in an extended school year program?

How and where do I apply for



Social Security for my son who has a disability?

You do not need to explain your story or request in detail to everyone. You don't have to give the medical terminology for your child's disability. Just keep it simple and straightforward. And keep it to the facts. It can be tempting to begin to explain the ins and outs of what you've been through; however, save that for your friends, family and support groups. Deal with administrators and service delivery people in a businesslike manner.

If the person is not available, simply say: *Please ask Ms. Claims Supervisor to return my call. My number is...*

If a message is requested, or if you volunteer to leave one, make it strong and to the point.

I am calling about the bus picking the kids up an hour early each day.

I'm calling about my son's application into the summer recreation program.

Ask when you can expect a return call. Write that down. If you don't get a return call when you should have, call back.

Call back if you don't succeed in reaching the right person the first time. Ask: *Who should I be talking to, then?* If they seem unhelpful or to be avoid-

ing you, write it down. Keep a record of these referrals and if they are passing the buck, say so: *Look, I'm getting annoyed. Mr. Blank referred me to Ms. Specialist who referred me to you and now you're referring me to Mr. Blank!*

If you are given approval over the phone, be sure to say thank you and ask for written confirmation to be sent to you the next day. File this with your other documentation.

• **Letter writing.** After the phone call, sit down and write a short letter stating that you just talked and summarizing the phone conversation. Keep it as objective as possible by stating the facts. At the top of the letter reference the subject:

"Re: Occupational Therapist Still Not Hired"

"Re: Second Request for Payment of Physical Therapy Sessions"

To give your letter real muscle, though, there's a simple technique called 'cc' or 'carbon copy'. This is at the very end of the letter and it's to let the recipient know that you mean business. You 'cc' your letter to their boss or to the head of the agency that administers the program. Using two or more cc's can be useful—you can 'cc'



Above: Helen Rader. Advocating for rights

Left: Joshua and his mom Jenifer actually testifying before Congress

Below: the IEP Team



an advocacy organization such as the national United Cerebral Palsy Association office or the affiliate, a parent training center, your state legislators and your U. S. Senator or Representative.

Don't worry about whether or not your congresspersons care. They do. This is one 'cc' that will do more good in the long run than any other. The people who amend, authorize funding or change the laws of the land need information from you. If there is no law or regulation, they can propose a new one. Your voice is very important. They need *you* to keep *them* informed.

• **Meetings.** If a meeting is scheduled at a time you aren't available, ask for it to be rescheduled. Propose an alternative time that is good for you. If you know that you are going to be late, call to let them know.

Be sure you know the purpose of the meeting. This will establish what

your role is and will help you to focus on what your child needs.

Be prepared. If you are going to change the IEP, have your suggestions in writing, preferably typed, with extra copies.

Take a moment at the start of the meeting to write down the names and titles of everyone in the room. Don't hesitate to ask: *Just a minute—how do you spell your name?* Introduce friends or advocates who you bring along for support.

Take notes during the meeting, if you can. If the meeting is 'going nowhere' say so and propose another meeting. You may want to bring a tape recorder.

If you don't understand something that is happening in the meeting, or if emotions flare, ask for a break. Say: *I think I need a break. I'm going into the hall for 10 minutes.* Use the time to collect your thoughts. Avoid being in a position where you swear or will later regret words you say.

If substantial gain is made during a meeting, write a follow-up letter to everyone who was at the meeting, stating what decisions or advances you believe were made and expressing

your appreciation. Send carbon copies of the letter to anyone interested in the outcome of the meeting.

• **Legal Representation or Alternative Dispute Resolution.** You can hire a lawyer later if you need to or you can opt to utilize a formal Alternative Dispute Resolution process if it's available or offered. Every state has a Protection & Advocacy agency and every county has a legal services office.

Documentation, knowledge of the facts and a feeling about what is going on are very important. You will save time, attorney's fees and personal aggravation if your records are in order. You will also know a great deal and be able to figure out if the mediator or lawyer is competent and knowledgeable about disability issues. You cannot assume that the domestic relations lawyer who you used for your divorce, for instance, also understands how special education law works, or that an appointed mediator knows what a personal assistance services care giver is.

Like all professionals you will be involved with, they are paid for their expertise and services—and it is you who hires or consults them. Always get several referrals and then "interview"

the professionals, if possible, to see if you can work with them. Again, trust your intuition and observations. You can say: *I'm shopping for an (attorney, doctor, dentist...) who understands disability. I'll get back to you when I decide what to do.*

• **Use of Anecdotes.** Anecdotes are stories told to make a point. They are used to give examples. Anecdotes are a particularly useful tool if you meet face-to-face with an elected representative, are asked to testify at a public hearing or meeting or are writing a *Letter to the Editor* for a newspaper. People remember anecdotes. For example, if you feel that the school system is unresponsive or insensitive to your child you could talk about your child's IEP goals and explain how they are not being implemented. Or, you could say: *My son Sean is in regular kindergarten. He can't talk. He uses sign language and a machine that talks for him when he pushes buttons. The teacher asked the children to bring in a favorite stuffed animal at story sharing time. Sean brought in his Snoopy, which he carries with him all the time. When it was his turn, the teacher wouldn't let him use his voice machine. She said it was disruptive*

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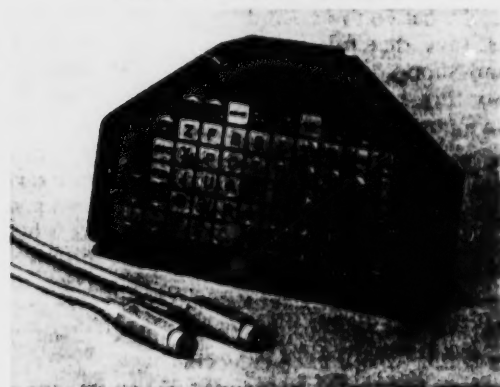
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and distracting to the other children. She has not learned his signs, so no one understood what he was doing with his hands. Sean stood in front of the class, silent. The teacher and children stared at him for a while and then she instructed him to sit down. He threw himself on the floor and had a temper tantrum. The teacher told the aide to take him out of the room for "time out." She then reported that Sean was becoming a problem child in her class and asked the principal to work out a behavior modification program.

A story in short declarative sentences is easier to understand than a lot of detail and opinion. Find a powerful story to make your point, and use it.

Advocacy is its own reward. And there will always be something to advocate for in this imperfect world. Accept that you cannot win all the time and that many goals may take months or years to reach. Give yourself a break now and again!

• **Pick your battles.** You'll have ample opportunity over the years to fight many, so choose them and space out your energy. And be creative—there is no limit to the tactics parents can choose as they advocate for what is right for their child with a disability. One parent may leaflet all the teachers' mailboxes to argue for inclusion of their child with Down Syndrome into a regular education classroom and win. Another parent may launch a full-scale litigation effort and win. Different circumstances require different actions and strategy on your part.

• **Celebrate your victories.** With each achievement, no matter how small, take a moment to congratulate yourself for a job well done. Have a party with your family or friends when you finally get Medicaid to pay for the specially-adapted toilet seat, when you secure SSI for your child or when you get the "okay for payment" for an extended school year over the summer. Share the gladness of the moment when your child gets on the bus with his sister to go to the neighborhood school, or when your young adult daughter with a disability gets a job after a year of searching.

• **Respect, not popularity.** You'll know you are an advocate when you feel like you have had to decide between being popular and being respected. In the long run, being respected will do more for your child than trying to keep everyone pleased.

This might sound like we're suggesting you have to fight for everything and be combative. We are not saying exactly that. We are saying, however, that as you work to make sure your child's legal and social rights are won—because, unfortunately, they are not automatically provided or extended to your child—you will feel and act differently. And it will be worth it!

It is your right, your responsibility and your duty to speak up and out. We thank you for your efforts. We all gain when your child gains.

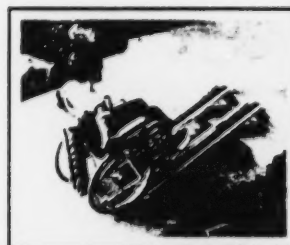
Helen Rader is an information & referral specialist and Jennifer Simpson is a policy associate in the national office of United Cerebral Palsy Associations, Inc., in Washington, D.C. They share 15 years of parent advocacy experience and have advocated on many issues with public and private sector entities. Ms. Rader's eight-year-old son, Will, has severe epilepsy and mental retardation. Ms. Simpson's seven-year-old son, Joshua, has multiple disabilities as a result of cerebral palsy.

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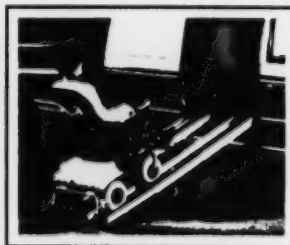


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A Place in the Dugout: Family Mainstreaming in a Rural Community

Sonya Smith



Left: Brian Smith is surrounded by his Dodger teammates

Below: Brian is joined by his sister, Rachael



The first time I heard the term mainstreaming linked to my son Brian, I dismissed it as someone's attempt to apply a trendy approach to the wrong child. As an educator who had worked in the area of special education for several years, I was aware of both the advantages and disadvantages of mainstreaming. Brian, however, was six years old and severely disabled. Sure, he was sociable and anxious to participate in school activities. But mainstreaming? I associated mainstreaming with kids who had mild learning delays or who were hearing impaired—the ones who at least looked like the other kids in the class. Brian was so severely spastic in his movements that he depended on others for everything.

As that germination year pro-

gressed, Brian's self-contained resource teacher mentioned more than once that the other kids in the class would be moving to the upper elementary school, and that the pre-school class at the lower elementary would dissolve. At first I panicked.

In the small rural community where we lived, Brian had been enclosed in a carefully constructed cocoon for the first years of his life. The infant stimulation center where he spent his first three school years was directed by a school nurse from the little community school where my husband had taught for several years. The pre-school class, his current setting, was located in a first grade facility where Brian's class was included in school activities. His principal would

visit the classroom, often sitting in one of the large rocking chairs and watching classroom activities. His teacher and therapists had become family friends, accompanying us to workshops and rehabilitation centers. Brian was a community project, cared for by everyone involved, including the only pediatrician in town, who helped make the initial diagnosis.



Sonya Smith

Why Mainstream Brian?

Everything was great, so why talk about mainstreaming? As a student in a university speech therapy program, I knew they were right. Brian needed language stimulation from his peers. As a mom, I dragged my feet. I worried about his safety. But I worried most about his acceptance by kindergarten children. I had little faith in the natural generosity of children. Other kids had never been unkind, just puzzled and aloof.

His teacher assured me that she would monitor the change, and that Brian would have a child-specific aide. I had made it clear that if the teacher couldn't provide a monitor, there would be no deal and Brian would continue in the self-contained classroom at the upper elementary school. She got the aide—the aide who had cared for Brian in the three years he had attended the lower elementary school. The principal got involved, saying they wanted to keep Brian one more year and this was the only way they could do it. I gave in. School



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ended and I worried until August.

School Begins

I met with his new teacher before school started. She had no experience with children with disabilities, not unusual in such a small town. She was hesitant, but willing to take on the challenge. What did I want for Brian, she asked. Just that people not make fun of him and stick him in a corner, I thought. I told her that I wanted Brian to feel like one of the group—not different, or special, but just a kid.

I peeked in the window during that first week. I even attended the first day of class. His former teacher broke the ice. She explained his problems and abilities, and the kids took it from there. He had a helper for the day to aid with his work and push his chair and had a special beanbag chair for circle time. When he got home, he had, for the first time, that wet puppy smell that comes from small children who play hard in a dusty playground and lie down for naps in a room hot from 19 little bodies.

Brian even had a special friend that year. Bill taught me more about mainstreaming than all of the articles I had ever read on the subject. He was always looking for ways that Brian could participate, rather than just watch. At the school Christmas program, Brian was on the stage, wearing his reindeer antlers, with Bill beside him determined that the antlers would not fall off and Brian would have a part.

I met Bill's mom at the class Christmas party. I was standing by Brian struggling to feed him a cupcake and trying to feel like one of the parents. In that department, Brian and his friends were doing a better job than we were. The grown-ups didn't know what to say, except that their children loved Brian, with a mixture of puzzlement and satisfaction in their voices. But Claudia, Bill's mom, broke the barrier and told me that Bill wanted Brian to come over during the holidays. I, like the other parents, didn't know what to say. Brian couldn't play or talk to Bill. What would they do? Bill took care of that. He presented Claudia with a list of things Brian could do, from having a parade to watching a video.

On the first visit, I forgot the beanbag chair and Bill reminded me to bring it next time so Brian could sit on the floor and watch movies too. Claudia and Bill invited us to community functions, and for the first time, we found ourselves mainstreamed along with Brian.

T-Ball

In the spring, T-ball and baseball became the solidifying factor in our community. There was one ball park and everyone participated, both boys and girls. Bill invited Brian to a game one Saturday, and the next day Claudia called to say that Bill's coaches had invited Brian to join the team. I accepted for him.

Brian was presented with a shirt, a cap and a place in the dugout. I was anxious, but I left him and joined the parents, where I realized that my anxiety was not unlike the anxiety of the parents of the kid who always struck out or of the girl who was relegated to right field and hit the ball a few feet if she hit it at all. I learned that I wasn't as isolated as I thought. Brian's dad even attended some games, and we laughed and discussed the kids and talked with people we knew.

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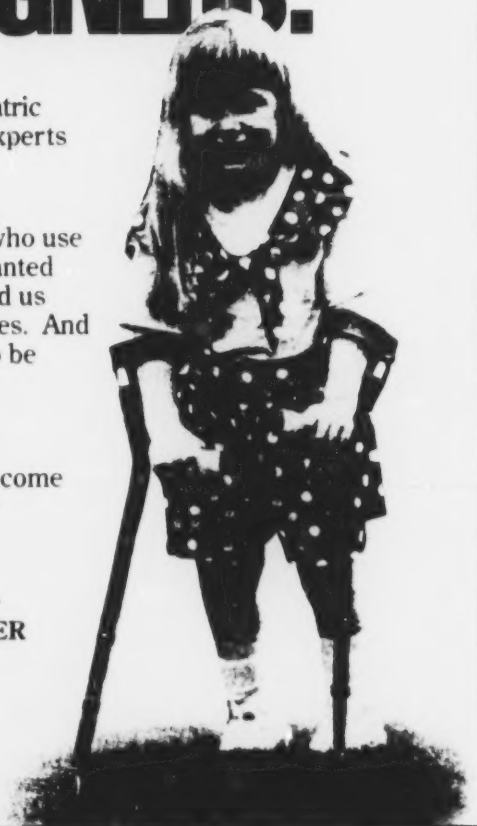
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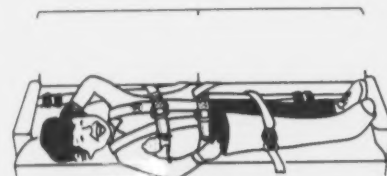
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We All Learned

I learned that letting go is an inseparable part of parenting, especially parenting kids with disabilities. That rural small-town school was limited in experience and equipment, but they made up for it in creativity, concern and a genuine sense of community.

Brian's T-ball trophy for participation sits on his dresser. It is a reminder for us and for him that winning means becoming a part of a team and giving what you have. Brian gave his enthusiastic presence and his unconditional appreciation for everyone who had a part in his kindergarten year. The school gave its willingness to turn a liability in terms of facilities and services into the asset of creative, thoughtful adaptation. Brian's classmates gave their willingness to look beyond Brian's limited body into his heart and spirit. Finally, Bill and Claudia gave us the encouragement and opportunity to know the joy and pain of complete parenting. ■

After teaching high school English for 10 years in rural central Louisiana, Sonya Smith returned to school 3 years ago to pursue a degree in speech pathology. Mrs. Smith, her husband, Bob, and their children Brian, 8, and Rachael, 4, recently moved to Denton, Texas. She will be working as a speech pathologist in the Denton area.

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Information from The National Parent Network on Disabilities

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- Patricia Smith, Executive Director, NPND

CONTENTS:

Disability advocate heads OSERS	83
Bob Williams New DD Commissioner	84
Message from the NPND President	84
NPND Dir. attends White House Mtg	85
Honorary Degree for Parent Advocate	85
Tribute to Cory Moore	86
Family support Legislation Drafted	86

NPND Celebrates Leadership
by Individuals with
Disabilities and Their FamiliesDisability advocate to
head OSERS

The U.S. Senate has confirmed President Clinton's nomination of Judith Heumann as Assistant Secretary of the Office of Special Education & Rehabilitative Services (OSERS), U.S. Department of Education.



Heumann was co-founder and vice president of the World Institute on Disability, a public policy/research/training organization based in Oakland, California. She succeeds Dr. Robert Davila.

After contracting polio as a toddler, she was excluded from her neighborhood school in Brooklyn, NY because her principal felt her wheelchair was a fire hazard. She then had 3 1/2 years of home instruction before attending a "health conservation" class for children with disabilities - in a school basement. Refused a teaching

position in New York schools because she could not walk, she sued successfully to become the first wheelchair user to teach in city schools.

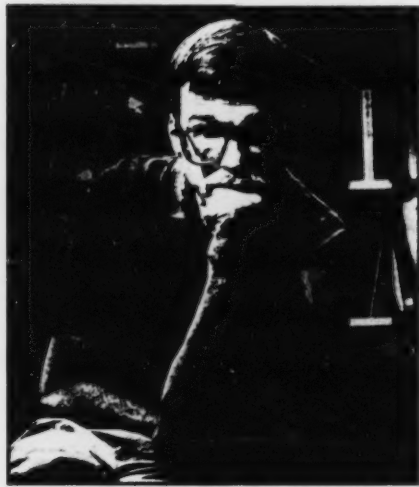
In the 1970's she was both an activist and a policy-maker. She participated in the Willowbrook deinstitutionalization/closure case. As a legislative assistant for the chair of the Labor and Public Welfare Committee, she worked on PL94-142 and Section 504 of the Rehabilitation Act. She also helped design California and federal independent living legislation before co-founding the World Institute on Disability 10 years ago with Ed Roberts.

In her new position, Heumann states that "I want to ensure that the issues affecting disabled people are seen as an integral part of the work of the Department of Education. I will work to provide for full and appropriate implementation of the Individuals with Disabilities Education Act. I will work to ensure that disabled children will benefit from the Administration's "Goals 2000: Educate America Act," and from the recently announced school-to-work initiative jointly sponsored by the Departments of Education and Labor. I will also work to ensure the full implementation of the recent amendments to the Rehabilitation Act, so that disabled people will have greater opportunities to achieve an independent life style. And I will work to implement the new Americans with Disabilities Act in my role as Assistant Secretary.

"More importantly, I will feel that I have accomplished my goal if we stop seeing the needs of disabled people as being special and different. I want to work with all of you to allow our government and society to see that we are part of the whole fabric of our country. To keep us on the sidelines reduces us to being a lesser nation."

Bob Williams Appointed DD Commissioner

On July 26th, the 3rd anniversary of the enactment of the Americans with Disabilities Act, Health and Human Services Secretary Donna E. Shalala



named Bob Williams to be commissioner of the Administration on Developmental Disabilities. Williams, who was born with cerebral palsy, has been a leader in the disability rights movement.

"Bob Williams, is the kind of person who reminds us again that we need to look at abilities, not disabilities, when we hire and promote," Shalala said of the appointment. "Bob brings with him a multitude of abilities that are needed in our HHS leadership".

Williams, 36, has been a policy associate with the United Cerebral Palsy Associations, Inc., spearheading the group's advocacy efforts in connection with the Americans with Disabilities Act and personal assistance. He has also been co-chair of the Consortium of Citizens with Disabilities' Rights and Personal Assistance Task Force.

"Bob is a nationally recognized expert on the best ways to create supports for people with disabilities to live, work and play in their communities," Shalala said. "He believes in community - not just as a place to live, but as a complete way of life, for all of us."

Prior to his service with UCPA, Williams was deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens. He also served as a program analyst for the Youth Policy Institute in

Washington D.C., and as a staff assistant on the U.S. Senate subcommittee on the Handicapped (now the Subcommittee on Disability Policy).

Williams has also been president of Hear Our Voices, an organization for people who rely on augmentative communication devices; and vice president of the Association for Persons with Severe Handicaps. He received a bachelor's degree in urban affairs from George Washington University.

A Message from the NPND President on National Leadership

Diana Cuthbertson

The National Parent Network on Disabilities is assuming leadership in school reform and the restructuring of school with the assistance of a planning grant from the DeWitt Wallace-Reader's Digest Fund. "All Children Belong" is an awareness and training program designed to build capacity within communities to more effectively support the learning and participation of children with disabilities within schools and in their communities. It focuses on opening doors for students and creating more options for participation in school, work and community activities.

Under the planning grant NPND learned from 53 Parent Training and Information (PTI) Centers and parent-to-parent programs around the country that "supported inclusive education", the opportunity to attend neighborhood schools with all necessary support, and community integration is a priority for 90 percent of the organizations. About 75 percent of the states represented are changing the way special education services are being provided to students. Not surprisingly, P.T.I.s indicated that they and the parents they support are committed to working hard to develop collaborative working relationships with educational professionals, as well as others in the community to assure that children with disabilities are included in general education classrooms, employment, and community life.

The next step for this leadership development at the state and local level is the implementation phase. NPND has completed its application to the DeWitt Wallace-Reader's Digest

Fund for the next portion of work which will be to provide information on education reform, school restructuring and the inclusion of students with disabilities at sites within 37 states. We will be using a train-the-trainer model (one parent trains another) to help people form collaborative, locally-based teams that can foster the inclusion of children in general education and/or community environments. The Statewide Parent Advocacy Network, Inc. (SPAN), a parent training and information center in New Jersey, has been pioneering this approach which is based upon information gained through federally funded statewide systems change projects for students with severe disabilities. The model begins with developing a positive student profile, identifying committed team members from all parts of the community, sharing a mission statement and operating principles, and collaborative teaming to help with on-going problem solving.

If NPND is successful in achieving on-going support of the Fund, the Network will utilize teleconferencing to convey the training nationwide. Parent organizations around the country will be networked via satellite to the primary training site and one another and learn more about developing Community Inclusion Action Teams. These teams, comprised of parents, educators, community leaders and concerned citizens, will promote the inclusion of students with disabilities and individualize supports to each person with a disability across the school building, school district and community activities. They will impact upon statewide school and social service policies as is necessary to bring about system-wide change.

Parent activism has been the driving force behind the inclusion movement in our country, however, it takes strong collaborative partnerships and committed leadership to make it work. "All Children Belong" will utilize the experience, energy and commitment of parents to catalyze community-based activities and promote on-going and effective support teams. If you would like more information about this project please contact Patty McGill Smith, Executive Director at the Network (703) 684-6763 or Gayle Hasslinger at SPAN (908) 654-7726.

NPND Director Participates in White House Meeting

Patricia McGill Smith, Executive Director of the National Parent Network on Disabilities, was one of 35 leaders from the field of disability invited to the White House on July 27th to mark the anniversary of the Americans with Disabilities Act.

To celebrate this occasion, President Clinton demonstrated the use of the telephone relay system with a call to Frank Harkin, brother of Senator Tom Harkin. The relay system technology makes easy communication with people who are deaf or hard of

hearing possible and July 27th was the date for the entire nation to be linked with the system.

The President's first experience in the use of the relay system resulted in a busy signal—a clear indication that the relay lines are being used—and something that, apparently, does not happen often to the President. The President and guests used this time to get to know each other and acquaint President Clinton with all the organizations represented.

After the telephone call Mr. Harkin was connected through the relay system, the conversation was typed on a large TV screen so the audience could see the exchange. The President reminded Frank Harkin that he was

the most famous "brother" in the nation since Senator Harkin spoke of him so often on the campaign trail.

When the call was completed, Mr. Clinton opened up the private meeting to dialogue with the participants. A good deal of time was spent on the issues relevant to the ADA and the President pledged his support. In addition, there was discussion regarding the concerns for people with disabilities in the area of health care and health care reform. Mrs. Smith, representing NPND, was able to add the needs of parents and families to the list of concerns.

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Room rates: \$79/single, \$89 double, \$99 triple or quad

Contact NPND Office for More Information 703-359-9484

Parent Advocate Receives Honorary Degree:



Florene Stewart Poyadue, Chief Executive Officer of Parents Helping Parents in San Jose, California, received an honorary degree, Doctor of Public Service, on June 13th from Santa Clara University. In her keynote address for the graduate commencement, Florene charged the graduates to "Do daily acts of human kindness, until we get the problem (of human relations) solved; and never underestimate your power of one to get a job done."

Networking is information from the National Parent Network on Disabilities. The Network is a membership organization open to all agencies, organizations, parent centers, parent groups, professionals, and all individuals concerned with the quality of life for people with disabilities.

Patricia M. Smith Executive Director
Connie K. Hawkins Editor

Media Buyers Guide

KEY: ➤ Books for Children ➤ Books for Parents & Professionals
 + Educational Materials ▼ Videotapes Ⓜ Audiotapes

➤ **Attainment Company's 1994 Product Guide** is available in September. Call or write for your free copy and see our latest products for education, communication and training. **Attainment Company**, P.O. Box 930160, Verona, WI 53593-0160, (800) 327-4269.

➤ **Educational Rights of Children with Disabilities: A Primer for Advocates** is a practical and up-to-date legal reference to help secure rights guaranteed under IDEA & 504. **\$15** (incl. s&h). **Center for Law & Educ.**, 955 Massachusetts Ave., Cambridge, MA 02139, (617) 876-6611.

➤ **Emily Good as Gold** by Susan Goldman Rubin. A teenager with a learning disability struggles with issues of sexuality and responsibility. **\$10.95** hardcover, **\$3.95** paperback. **Harcourt Brace & Co.**, 1250 Sixth Avenue, San Diego, CA 92101 or call toll-free (800) 543-1918.

➤ **Finding The Perfect Childcare** A Step-by-step guide full of tips, checklists and worksheets for finding, interviewing and hiring the best-care for your child. Send **\$8.95**: **Checkpoint Press**, 872 S. Milwaukee Suite 270 Dept. EP, Libertyville, IL 60048.

➤ **Free Book Catalog: The 1992 Special Needs Catalog** features a collection of valuable books for children with disabilities and their parents on Down Syndrome, CP, autism, spec. ed. and more. Please contact **Woodbine House**, 5615 Fishers Ln., Rockville, MD 20852, (800) 843-7323.

➤ **Free-The NEW Special Needs Project Book Catalog.** Selection of the best books from all publishers about disabilities. Comprehensive resource for parents, children & prof. **Special Needs Project**, 1482 E. Valley Rd., #A121, Santa Barbara, CA 93108, (800) 333-6867.

➤ **Mom, I Have a Staring Problem.** by Marian and Tiffany Buckel. A true story of petit mal seizures and the hidden problem it can cause: learning disability. Illustrated book provides insight. **\$3.95** or **\$4.23** FL residents **Marian C. Buckel**, P.O. Box 69233, Orlando, FL 32869-2633.

➤ **Parents' Newsletter on Special Education Law.** This 12 page, bi-monthly newsletter helps parents protect their child's legal rights to an appropriate public education. **\$29** for six issues. Free sample copy. **Parents' Newsletter**, P.O. Box 4571, Chapel Hill, NC 27515-4571.

➤ **Prader-Willi Perspectives.** A quarterly journal that is a must for parents and professionals--now in its second year of publication. **\$20** /yr. (individual), **\$30** /yr.(organization). **Visible Ink, Inc.**, 40 Holly Lane, Roslyn Heights, NY 11577, (800) 358-0682

➤ **Turtle Books: Sensitivity & Awareness User's Guide for TURTLE BOOKS.** Use with elementary and middle school children. Send for sample session and for a free Turtle Book brochure to: **Jason & Nordic Publ.**, P.O. Box 441, Hollidaysburg, PA 16648.

➤ **Special Angel - An Introduction to Down Syndrome** by L.T. & M.P. Nolen. Excellent "first book". Quality photos, resources & reading materials. **\$9.25** "Up with Down Syndrome" T-Shirt **\$13.50**. Free brochure. **Graffiti**, 13302 Ravenwing Dr., Cypress, TX 77429 (713) 894-9210.

▼ **Expanding Access Expanding Horizons** by Marilyn Hammond. Video explores computer hardware and software as well as some other electronic devices. **\$26**. **Utah Assistive Technology Program**, Utah State University, UMC 6855, Logan, UT 84322-6855 or call (800)-333-UTAH

▼ **Gopen's Guide to Closed Caption Video.** 560 pages with 23 categories and 5,000 titles. Program descriptions, running times, ratings, prices. Check or MO for **\$14.95** (+\$3.50 s&h). **Caption Database, Inc.**, 1 Walker's Way, Framingham, MA 01701. Call (508) 620-6555 (Voice), (508) 620-6222 (TDD).

▼ **Interax Video Sign Language Course.** Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. **\$199** (+\$4.50 s&h). **Interax Training, Inc.**, P.O. Box 473106, Garland, TX 75047-3106, (800) 242-5583.

▼ **Pick 'n Stick®**, Primary Pack & Touch 'n Talk® boards and notebooks. Books and videos for helping parents stimulate language development. Swallowing and feeding materials. Free Catalog. **ImaginarT**, 307 Arizona St., Dept. EP, Bisbee, AZ 85603, (800) 828-1376.

▼ **The Sky's the Limit** by Marilyn Hammond. Award winning video features recreation for children and adults with disabilities, focusing on things we can do. **\$26**. **Utah Assistive Technology Program**, Utah State University, UMC 6855, Logan, UT 84322-6855 or call (800)-333-UTAH

➤ ▼ **All by Self** (book). Inspiring father-son story that helps parents express feelings, and children to better understand and accepts "special" classmates. Resource guide at end. **\$12** (+\$2 s&h). **Happy Birthday** (videotape). A day in the lives of 4 children with different disabilities as seen through their eyes. **Think About It**. One of 1991's ten best short videos. A music video (with study guide) that stimulates lively discussion about diversity. Surprise ending challenges our concepts of "us" and "them". To preview videotapes, send **\$5 each**. Catalog of special videotapes: **Light On**, Box 8005, Suite 358, Boulder, CO 80306, (800) 444-3340

Tribute to a Leader— Cory Moore

Cory Moore, parent, teacher, advocate, and friend died of cancer at her home in Bethesda, Maryland, on May 3rd.

Cory was the founder of the Parent's Place of Maryland, a parent training and information center. As co-director of the Parent's Place, she provided leadership in the move towards inclusive schools, worked to enhance parent-professional partnerships and to improve post-school services for persons with severe disabilities. Cory had also served as a community organizer for the Maryland Coalition for Integrated Education where her efforts helped to provide a national vision of the value of full school inclusion for students with disabilities.

Cory's Book, *A Reader's Guide for Parents of Children with Mental, Physical, and Emotional Disabilities*, is a classic reference guide that is extensively used in parent education programs and many colleges and universities. She was also the author of many articles that supported the value of parent participation and inclusive programs.

Cory is survived by her three children along with a sister and brother. Her family requests that memorials in honor of Cory's life be made to the Parents' Place of Maryland, 7257 Parkway Drive, Suite 210, Hanover, Maryland 21076-1306.

Cory was a gentle leader whose humor and ability to tell a story helped parents nationwide define their own "visions." She will be missed.

Family Support Legislation Drafted

The members of the children and Families Task Force of the Consortium for Citizens with Disabilities (CCD) have completed the drafting of "Children with Disabilities Family Support Act". This proposed legislation was completed as "Networking" was going to press. The task force led by Alan Bergman from the United Cerebral Palsy Associations, Barbara Huff from the Federation of Families for Children's Mental Health and Patty McGill Smith from NPND, met all Summer to complete this draft. The draft legislation has had strong interest from members of Congress. The following is a portion of the proposed legislation:

II. Purposed

It should be the policy of the United States to provide financial assistance to States to encourage and assist the States to plan and create a statewide family support policy initiative:

A. To enable the families of children with disabilities or with chronic illness to nurture and enjoy their children in their homes rather than supplanting the family's primary caregiver role by expanding public funds to place the children in institutions or other out-of-home placements:

- B. To enhance the quality of family life;
- C. To support, strengthen and preserve families who are caring for their children with disabilities or chronic illness in their home;
- D. To ensure the local availability and coordination of and;

Federal and state governments should develop policies for, finance, and evaluate family support in accordance with the following principles:

- A. Importance of family setting and home life: All children, regardless of the type of severity of their disabilities, belong with and do best with families. All children have a right to a safe, permanent, stable and nurturing family relationship in the family home and in the community. Accordingly, families should receive whatever support they deem necessary, desirable and appropriate to care for their children with disabilities or with chronic illness at home and to prevent the unnecessary separation of children from their families. Family support is proactive and not a response to a crisis.
- B. Focus on the whole family: Family support must focus on the heads of the entire family, not just the needs of the child with a disability or a chronic illness and must be family-centered.
- C. Flexibility: Family heads change over time and family support must be flexible and responsive to the unique.

NPND Invites You to Join

Mission:

The National Parent Network on Disabilities (NPND) was established to provide a presence and national voice for parents of children, youth, and adults with special needs. NPND shares information and resources in order to promote and support the power of parents and resources to influence and affect policy issues concerning the needs of people with disabilities and their families.

Membership Fees

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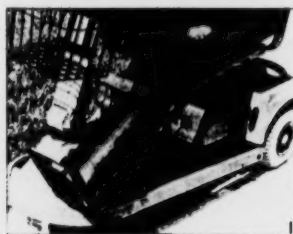
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Product Showcase



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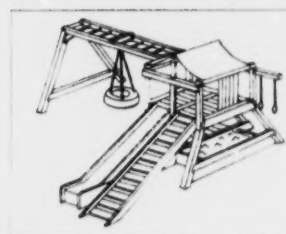
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Directory of Advertisers

Advertiser	Pages	Advertiser	Page#
Abilities Expo	36	homecare Products	77
Above	12	HMS School	D13
Access Able	13	imaginart	32
Adaptive Design Lab	12	Innovative Products	8
Agape Village	D6	Jay Medical	inside front cover
Annandale at Suwanee	D19	Kid-Kart	7
Anne Carlsen	D2	Koiburne School	D21
Assoc. for Birth Defect Children	30	Laureate Learning	76
Attainment	66	League School	D17 D21
Bartlett Learning Center	D19	Learning Center	D21
Behavior Research	D6	Light on Publishing	27
Berkshire Meadows	D24	Marblesoft	20
Bethesda Lutheran	D9	Martha Lloyd	D12 D21
BHC: JA Preston	back cover	NE Center for Autism	D8 D14 D16
Braun Corporation	93	NE Villages	D17
Brehm School	D19	OmniCare	81
Bruno	16	Opus Marketing	89 91
Camp Huntington	D19	P. L. Corporation	21
Challenges Unlimited	66	Pathfinder Village	72
Charles C. Thomas	95	Phonic Ear	72
Chieda Habilitation	D19	P. I. Bear	20
Chrysler	11	Plum Enterprises	1
Chrystal Springs	D9	Quicke Designs	5
Columbia Medical	69 71	Radventure	32
Consumer Care	28	Rhamec	33
Crotched Mountain	D6	Rifton Inc.	91
Crow River	79	RJ Cooper	82
Danmar	70	Rollins Healthcare	27
DCMK	70	Rugby School	D19
Developmental Schools	D11	Sentinel Systems	34
Devenius	D4 D19	Special Designs	10
Duval Home	D19	Tall Pine Camp	D5 D10
E-Z-On	81	St. John's Villa	D18
Ehryn	D19 D22	Stewart Home School	D18
Equipment Shop	81	Sunshine Rehab	D21
Estate Planning	21	Tall Pine Camp	D21
Evergreen	D11	TASH	76
Flaghouse	90	Teddyne Brown	2
Garaventa	24	Toto Kid	35
Gillette Childrens Hospital	14	Triad	66
Groden Center	D21	Visible Ink	13
Hacienda de los Angeles	D13	Voornhees Pediatric	21
HDIS	24	Walk Easy	80
Hearnspring	D14	Woodburn	82

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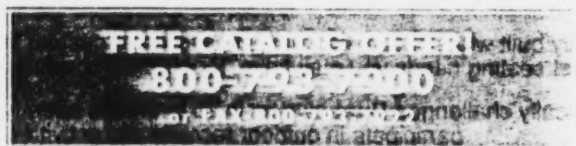
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DB-LINK collects, organizes and disseminates information via a consor-

tium-based project comprised of American Association of the Deaf-Blind, American Foundation for the Blind, Hellen Keller National Center, Perkins School for the Blind, and Teaching Research of Western Oregon State College.

At present, DB-LINK does not charge for its service. Consumers can speak with DB-LINK information specialists from 9 a.m. to 5 p.m. (EST) at (800) 438-9376 or (800) 854-7013 (TTY). Or, write to DB-LINK, 345 North Monmouth Avenue, Monmouth, Oregon 97361.

National Registry for Retinopathy of Prematurity

The organization Prevent Blindness in Premature Babies announces a national registry for people with the eye disease retinopathy of prematurity, ROP (formerly called retrolental fibroplasia, RLF). This is the first registry of its kind in nearly 50 years of epidemic. ROP, a disease that affects premature babies, prevents the eye from developing properly and can lead to permanent damage and blindness, even later in life. ROP is more responsible for blindness among children in this coun-

try than all other causes combined. The purpose of the national registry is to show the government that the prevention of ROP is an issue of utmost importance that must be addressed immediately. If you (or your child) were born prematurely and have any degree of vision problem, please write to request a newsletter and survey.

For more information, contact Prevent Blindness in Premature Babies, P.O. Box 44792, Madison, WI 53744-4792.

On-Line Bulletin Board for ADD

C.H.A.D.D. *On-Line* is an electronic bulletin board and database of information for parents of children with ADD, adults with ADD educators, health care professionals and researchers. This bulletin board, part of the ADD (Attention Deficit Disorders) Forum, is available to CompuServ subscribers.

In a little over three months, computer users posted more than 6000 messages ranged from questions (*My child has just been diagnosed--what do I do next?*) to announcements (*Exhibitor booths are still available for 1 C.H.A.D.D. conference.*) Thousands interested in ADD have loaded free files onto their computers over the last few months. The files contain information such as ways of diagnosing and treating people with ADD, tips on how best to manage children with ADD at home and in school, legal issues and advice on how to select a babysitter.

For information on Children with Attention Deficit Disorders (C.H.A.D.D.) call the national headquarters at (305) 587-3700. To find out more about C.H.A.D.D. *On-Line* and the ADD Forum, contact Herb Meyer at (212) 724-9699. To join CompuServ, call (800) 848-8990.

Careers and Technology Information Bank

The American Foundation for the Blind (AFB) has announced the addition of a new program to its popular Careers & Technology Information Bank. The new program offers students who are blind or visually impaired the chance to learn about job experience and assistive technology from mentors and advisors who are blind or visually impaired.

AFB established the Careers & Technology Information Bank (CTIB) in 1986 as a job and product information source for people who are blind or visually impaired. Today, the CTIB is a network of 1500 members from all 50 states and Canada who use assistive technology at home, at work or at school. A database of information, including personal histories, education, careers, and the purchase, training, and use of assistive technology, has been created based on interviews with each member. Members agree to speak with students about how they accomplish the tasks of their jobs or educational programs.

For more information, contact Careers & Technology Information Bank, American Foundation for the Blind, 15 West 16th Street, New York, N.Y. 10011, or call (212) 620-2080.

College Goals

"Where do we go from here?" is a question often asked by parents and students with disabilities at the high school level as graduation approaches. Education is one of the keys to independent living for people with physical disabilities.

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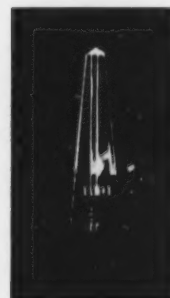
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This is why my "next father of the year" shall be that, because, you see he lives on the tradition of the Christman family and will continue to do so after he dies and when I, Kevin William Christman, live in the spirit of Robert Charles Christman and forever and ever and ever!



Kevin is 11 years old and uses a wheelchair. He is in a totally mainstreamed classroom and uses two fingers to write essays on a computer. He will be entering Wantaugh Middle School in September, 1993. Kevin has received several awards, such as the Wantaugh Elementary School Kennedy Award for good citizenship and contribution to the school and the *Sports Illustrated for Kids* award for "Someone Who has Made a Difference in My Life," an essay about Police Officer Steven McDonald. He also wrote the winning letter for the "Father of the Year" contest. Kevin lives with his parents, Linda and Robert, and his brother, Brian.

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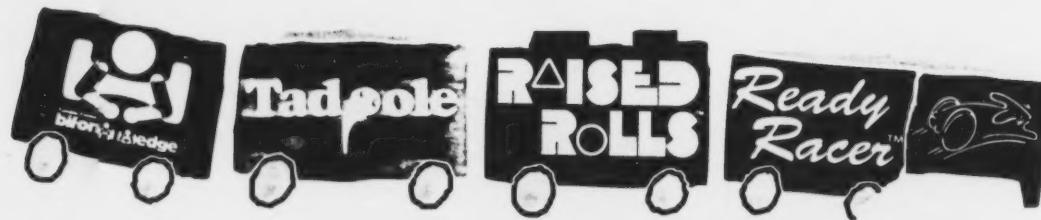
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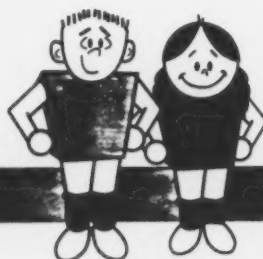
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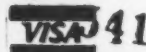
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Exceptional Parent

PARENTING YOUR CHILD WITH A DISABILITY

October 1993

Volume 23 Issue 8

FEATURES

18 Choosing Holiday Toys

How to select gifts that suit you and your child.

23 A Fine Purpose *by Carol Abbott*

A mother realizes that her son's short life had purpose—to teach unconditional love.

28 Health Care Reform: Getting to the Heart of the Matter

by William Sciarillo

Advocates for children with disabilities need to voice their concerns.

40 Developing Your Own ILEP *by Ruth A. Wilson*

Parents' needs are important, too.

44 Purchasing a Hearing Aid

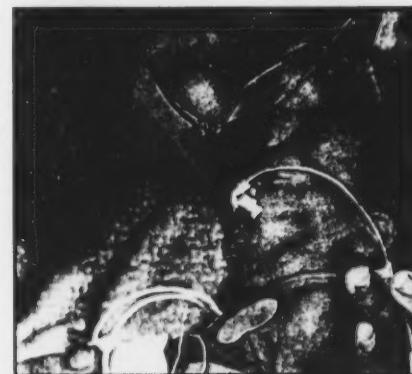
Tips for parents of children with hearing impairments.

46 Update on School Bus Safety *by Roseann Schwaderer*

Current developments in transportation safety



Page 23



Page 28



Page 49



COVER

Jonathon Den
meets Kevin
McHale while
celebrating his
Bar Mitzvah
read Jonathon's
speech on
page 62.

Cover Photo: Harold Summers ©1993

DEPARTMENTS

- 4 Editor's Desk
- 6 Letters
- 8 Family Support
- 35 Media
- 42 Editorial
- 49 Fathers' Voices
- 53 Opinion
- 58 What's Happening
- 62 Children's Page

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EDITOR'S DESK



Stanley D. Klein Ph.D.

After Jonathan Derr successfully completed the religious parts of his Bar Mitzvah, including the moving speech published in this issue, he put on his tuxedo and went with his family (and photographer Harold Summers) to a reception at a nearby country club. Just as he arrived, Boston Celtic star Kevin McHale was finishing a round of golf and was happy to congratulate Jonathan, an avid fan, on his wonderful accomplishments. We thank Jonathan and his friend Kevin, a celebrity who does a great deal for children, for appearing on our cover.

In this issue

"Choosing Holiday Toys" was prepared to help readers begin planning for the holiday season while "Developing Your Own IEP" reminds parents to be sure to remember their own needs. "A Fine Purpose" tells the moving story of a caring family coming to terms with their child's life and death. Because hearing impairments are common among children with various disabilities, we appreciate being able to adapt ASHA's publication on "Purchasing a Hearing Aid."

By the time you read this, President Clinton and other leaders will have presented proposals for reforming the health care system. In "Health Care Reform: Getting to the Heart of the Matter," William Sciarillo shares his insights on this critical public issue. Because health care reform demands everyone's attention, our editorial also addresses it. In the March issue, we reported on the controversy over safe transportation for children with special needs on school buses. In this issue, we detail current developments.

Changes

At the end of August, we moved our editorial office a short distance to Brookline, Massachusetts. At the same time, we completed the process of moving to our new publishing office in Hackensack, New Jersey. More importantly, I am delighted to announce that Kim Schive has joined us as an Assistant Editor. Kim brings many talents to our editorial office. A former editor of *Deaf Community News* (published by the Massachusetts State Association for the Deaf), *The Endeavor* (published by the American Society for Deaf Children) and *Soundings* (published by the Massachusetts Parents Association for the Deaf and Hard of Hearing), Kim has a Masters degree in psychology from Harvard University and has taught at Harvard, Boston University and Gallaudet University. Kim is a deaf adult and the adoptive parent of a deaf child with disabilities who is now 18 and a high school senior.

New Departments

As Project Director of the National Fathers Network, James May travels across the country working with fathers and fathers' groups. James is also a member of our Editorial Advisory Board. Beginning with this issue, Fathers' Voices by James May will be a regular department; James looks forward to hearing from readers, including mothers and others! Opinion is another new department open to all our readers. In this issue, Lisa Blumberg shares her perspective on inclusion and education. Long-time readers know that Lisa, also a member of our Editorial Advisory Board, has written about many important topics on the pages of *Exceptional Parent*. Other new departments are on the drawing board—readers' suggestions are always welcome.

Coming in November

The November/December issue will be our Eleventh Annual Computer/Technology issue, featuring up-to-date information for experienced technology users as well as novices.

1994: 12 issues!

I am delighted to announce that beginning in 1994 *Exceptional Parent* will be a monthly magazine. Readers' subscriptions scheduled to expire during 1994 will expire on schedule—that means those readers will get more issues than expected. New subscriptions will be adjusted accordingly.

Exceptional Parent

Parenting Your Child With A Disability

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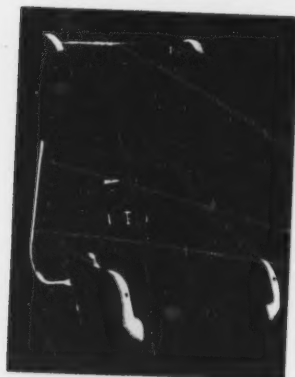


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Letters to the Editor

Labels

■ As a parent of three children, one of whom has Down Syndrome, I struggle daily with society's negative stereotyping of individuals with mental handicaps. I am particularly saddened and angered by the response of another parent to the apparent mix-up in terms between "learning disability" and "mental retardation." (Letters to the Editor, July/August 1993—"Film's Description Wrong")

I am quite aware of what the label "mental retardation" does to an individual's value in this culture. I am certain that this parent's motives are to ensure that children with learning disabilities are not similarly devalued.

Maybe the goal of parents like us should be to work toward nurturing our children's innate gifts, potential and ability to achieve. Shouldn't we, of all people, understand that an attitude which seeks to separate ourselves from others on the basis of disability is destructive to everyone? It would be nice to know that the "network of support" enabling them (children with learning disabilities) to achieve all they can despite some differences could be extended to all children—yes, even those who "by definition, have less-than-normal intelligence and need other kinds of help."

M.P.
Indiana

■ I have been distressed to see that, even among those who profess to work on behalf of people with disabilities, the issue of labeling is of major importance. As was written in the last issue of *Exceptional Parent*, the Learning Disability Association was upset that a child with Down syndrome was labeled as having learning disabilities instead of being labeled "mentally retarded".

In my own community, I attended a meeting last week to hear a college professor speak about the Americans with Disabilities Act (ADA). Speaking of her conferences with leaders in industry where she lectures on compliance with ADA, she stated that she says "Just because they can't walk, and they sit in their wheelchairs, doesn't mean that there is anything wrong with their heads!"

A speech and language pathologist told me of the outcry from parents of some of her child clients with hearing impairments when a child with Down syndrome was selected along with other children to appear as a poster child for Better Speech and Hearing month.

Are children labeled as learning disabled more valuable than those with other labels? Is it "better" to use mobility aides than to have difficulty reading? Does it matter if speech difficulties are caused by a hearing impairment or by a genetic condition? Since many of those advocating for people with other disabilities want to be so sure that the public understands that their disability is not connected with mental retardation, does that mean that those with cognitive developmental delays are at the bottom of the pile, and are least deserving of services?

Isn't it time that all of us realize that what we do for people with one type of disability directly impacts people who have another type of disability? Isn't it time that we realize that elitism has no place in the world of disability, that one disability is not "better" than another, and that wonderful individuals can have any one of the labels that tell of their disability, yet remain wonderful folks?

Labels are valuable when they tell us how to approach individuals and how to meet their individual needs. But they are harmful to all of us if they are used to set up a "pecking order" among disability groups, parents, or the public in general.

P.P.
Ohio

■ I would like to point out that nowadays, with increased availability of early intervention, enriched education and inclusionary school programs, more and more children with Down syndrome are qualifying for, and participating in, programs designated for children with learning disabilities.

My own son with Down syndrome, now 19, has been in learning disability classes since he was 5 years old. He has flourished in these classes, kept up with the academic curricula and maintained honor roll grades, frequently at

the top of the class. He will graduate from high school next June with a regular, full academic diploma.

Obviously, not all children with Down syndrome will be able to achieve on these levels and succeed in these kinds of classes. But those who can certainly should not be denied access to academically appropriate classes or programs because of their label or diagnosis.

Interestingly, the biggest obstacle we encountered to our son's acceptance in learning disability classes was the resistant attitude of the parents of the other children in the class. Since most youngsters with learning disabilities "look normal," the parents were concerned that the presence of a student with Down syndrome would negatively stigmatize their children by association. They said that even though my son's academic performance was often way ahead of most of their kids'.

I suggest that we not be so hung up on labels and terminology but let all kids receive the opportunities and support necessary to maximize their potential. We know now that intelligence, performance and ultimate success in life cannot be reduced to an IQ number. It does not benefit anybody to arbitrarily lump some kids into the "normal-or-above-average" group and consign others to the "less-than-normal" group according to the number of chromosomes they have.

I eagerly look forward to a day when youngsters are recognized and appreciated as individuals, with individual strengths and weaknesses, capabilities and deficits, individual interests, talents and needs and individual abilities to make contributions to society—a day when the labels become irrelevant.

E.P.K.
New York

We welcome all letters from readers—reactions to articles, suggestions, opinions, complaints. Write or fax:
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Parent's Search

Excessive Weight

My son is 20 years old and has been through several surgeries and long hospital stays. Along with his bowel and bladder incontinence (from birth), hormone deficiency, blindness in his left eye, and deafness in his left ear, he's a 350 lb. 5'5" young man and steadily becoming heavier. He is developmentally delayed (physically and mentally), although he has shown great improvement within the last four years. He's a very loving and sensitive person. Eventually we might have to face amputation of both legs, due to poor circulation. He was born with spina bifida. I've been reading *Exceptional Parent* for four years and the only topic I haven't come across is older children with spina bifida and their incontinence.

I really would like to receive more information concerning children older than 15 with multiple disabilities and excessive weight gain. I'd also like to hear from people who have experience with bowel incontinence and have suggestions for how I can help my son. Thank you.

M.B.
Missouri

Undiagnosed

I'm searching for a match. I hope you can help. My daughter was born July, 1987. She is undiagnosed at this time. I'm looking for someone like her or with similar problems. She was born with no gums, cauliflower small ears, and no flare around her nostrils. Her fingernails and toenails have indents in them. She needs to get some teeth. I have found no one who has had bone replacement for gums or used dentures on small children. Can anyone help with information?

D.V.
Wisconsin

Diagnosis?

We are hoping someone can help us to find a diagnosis for our four-and-a-half-year-old daughter, Lauren. She appeared to be a normal, healthy infant, although she seemed tired, weak, and a little shaky. When it

came time to crawl and walk, we noticed that she was delayed.

Blood work at 12 months showed an elevated liver enzyme and LDH, and low blood sugar. The doctor also told us that he thought she had a mild glycogen storage problem. At 26 months she went into convulsions and after going to a children's hospital we were told that she had viral encephalitis although the MRI also showed possible leukodystrophy.

Since that time she has not recovered well. She has brain damage, a seizure disorder and no speech. She has to use sign language. Now doctors tell us that they don't know what she had but that it may be a genetic disease.

She has been checked for metabolic disorders and also for a mitochondrial disorder. So far, nothing has shown up on the tests.

She now has a one-year-old sister that we are also concerned about.

Does this sound familiar to anyone? Has anyone out there dealt with something similar?

R.A. & D.A.
Illinois

Prematurity

I am the parent of a very premature baby: he was born at 24 weeks and weighed one pound, eight ounces. He has BPD (bronchopulmonary dysplasia), is developmentally delayed, and has had laser surgery and cryotherapy on his eyes.

I would like to hear from other parents of very premature babies. I am especially interested in preemies who are now school age. I would like to learn more about their development through the first few years of school.

L.H.
Michigan

Cochlear Implants?

As a result of a viral infection during the first trimester of pregnancy (CMV), my 13-year-old son, Nathan, has multiple disabilities. He has a seizure disorder and profound hearing impair-

ment. He is non-verbal, non-ambulatory and spastic quadriplegic. In spite of his disabilities, he is a joy to his family and all those who know him. Nathan currently attends sixth grade in his home school. He is very aware of his surroundings but his hearing impairment has really been a problem in trying to design a communication system.

I am currently pursuing information on cochlear implants and am interested in hearing from parents whose children have had the implants and whose disabilities are similar to Nathan's. I would like to hear both pros and cons.

C.A.
Montana

Biofeedback?

I am the parent of an 11-year-old boy with spastic cerebral palsy with involvement in all four extremities and some speech involvement. I am interested in hearing from anyone who has ever used biofeedback with their child.

L.F.
Iowa

G-Tube?

My son Joseph was born at 28 weeks. He weighed one pound, ten ounces and suffered a Grade IV brain hemorrhage. He is presently 28 months old and is unable to hold his head up for extended periods of time, or feed or sit by himself. He weighs less than 18 pounds and is on Pedisure formula and sustal pudding. We also supplement with pureed baby foods. His developmental doctor has suggested that we consider a G-tube placement, however, I wonder if he would benefit since he also has reflux.

Also, our son is very unhappy whenever he is put in his carseat and we are unsure if this problem is further complicated by his visual delay or because of his difficulty separating. I would love to hear from any other parents who are dealing with these problems.

T.G.
New York



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Editor's Note: Discuss your questions about the use of a G-tube with your doctor. Ask about a referral to a special feeding clinic in your area so you can get more information about your concerns.

Early Myoclonic Encephalopathy

Our son, five-and-a-half-month-old Austin, is diagnosed with Early Myoclonic Encephalopathy Syndrome (EME). Austin's seizures began 12 hours after his birth and presently manifest as a single seizure followed by a series of extensor spasms. These episodes occur between 3 and 24 times per day. He also has a continuously abnormal reactive burst suppression EEG pattern and cortical blindness. The cause is unknown, as CT scans, MRIs and all metabolic tests are negative.

Developmentally, Austin is still a newborn. He has no head control and his movement is limited to wiggling of fingers/toes. He has perfect hearing, sometimes coos and seems to know and respond to us. He is getting a G-tube since he has lost his suck and swallow due to his current medication combination of

Nitrazepam, Valproic Acid and Phenobarbital. He has previously been on Dilantin, Tegretol, ACTH and Clonopin. His seizures have never been controlled.

We also want to mention that Austin was conceived while we were using the contraceptive sponge with Nonoxynol-9 (spermicide). It was used again at four to four-and-a-half weeks after conception, at the time Austin's brain and nervous system were forming, since I didn't expect to be pregnant. We had two healthy children before Austin.

Since EME is extremely rare and NORD has no listing we are eager to hear from other parents of infants/children with EME or burst-suppression EEGs. We would also like to know if any parents out there used Nonoxynol-9 (in any form) at conception or during pregnancy and gave birth to a baby with any type of problem.

M.D.
New Hampshire

Microcephaly

My son Jack was born with microcephaly. He is ten months old and is in therapy. I really am desperate to

hear from parents who have a child with a similar disability. I can't seem to find any other parents in my area who have similar problems. I really feel alone and don't know much about this disability, so please, if anyone is going through this, I would like to hear from you.

J.G.
Illinois

Editor's Note: There are two Parent Training and Information Centers in Illinois. Call each for help connecting with parents who have a child with a similar disability.

• *Designs for Change, 220 South State Street, Suite 1900, Chicago, IL 60604; telephone: (312) 922-0317, (800) 952-4199.*

• *Family Resource Center on Disabilities, 20 East Jackson Blvd., Room 900, Chicago, IL 60604; telephone: (312) 939-3513, (312) 939-3519 (TDD/TTY), (800) 952-4199.*

Using a Van Driver

I anticipate purchasing an accessible van for myself in the near future. I have epilepsy, however, and until I have remained seizure-free for the time required in my state, I must use a driver to transport me in my van.

I am interested in hearing from other individuals who have drivers. I want to know how convenient it is (compared to public transportation), how much drivers are paid, how scheduling is handled, etc.

S.B.
Kansas

Diabetic, A.D.D., Developmentally Delayed

I am a single mom of a seven-year-old diabetic, ADD, developmentally delayed girl. For one year I have been trying to find a child with ADD and developmental disabilities. I have tried parents' groups but no one understands the challenges I have to go through alone with a child with ADD, developmental disabilities and diabetes. My child went through educational discrimination when she was between four and five years old because of her diabetes. I educated myself to become an advocate for her and won two times so she could attend a preschool.

It took three years to find a school system that would accept my

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child with her diabetes. My daughter became developmentally disabled due to a diabetic coma three years ago. She may be seven but has the IQ of a three- to four-year-old. Any parent of an ADD and developmentally disabled child please write.

A.A.
Ohio

Editor's Note: There are two Parent Training and Information Centers in Ohio. Call each for help connecting with parents who have a child with a similar disability.

- Child Advocacy Center, 1821 Summit Road, Suite 303, Cincinnati, OH 45237; telephone: (513) 821-2400.
- Ohio Coalition for the Education of Handicapped Children, 1299 Campbell Road, Suite B, Marion, OH 43302; telephone: (614) 382-5452 (VOICE/TDD), (800) 374-2806.

G-Tube

I am the parent of a 13 month old with a G-tube. She was hospitalized for eight months in three different states. She was finally diagnosed with small bowel disease, dumping syndrome and malabsorption disorder. After several surgeries and the use of a rare formula, she is finally home.

Falon attends occupational and feeding therapy five days a week. She does not eat or drink anything by mouth. I have tried everything and still no progress has been made. She will not open her mouth for food or the cup. If I am able to "sneak" a spoonful into her mouth, she will spit it out instead of swallowing. I am told this behavior could last two to four years. This means the G-tube will be in for a very long time. I would be so grateful to hear from other parents with this problem. I feel so upset and hopeless.

L.R.
Florida

Mitochondrial Myopathy

Tony, age three, has been diagnosed with mitochondrial myopathy with carnitine deficiency. He also has seizures that started at age two. He has lost all speech, is very tactile-defensive, especially around the face, and shows autistic tendencies. Sometimes he seems to have problems eating anything but soft food. His attention span is very short except

for physical activities such as swinging. He doesn't play with toys but will find a favorite for a week or so and carry it with him everywhere. Can anyone help?

C.C.
Idaho

Cri-du-Chat, Tetralogy of Fallot

My daughter is 12, years, old and has Cri-du-Chat syndrome, #5 chromosome; she also has Tetralogy of Fallot, a congenital heart defect. Although I have information on both, I have never been able to talk to other parents of children with the same syndrome. I would really like to hear from other parents.

J.S.
Tennessee

Editor's Note: For help connecting with parents who have a child with Cri-du-Chat Syndrome, contact The 5p-Society, 11609 Oakmont, Overland Park, KS 66210; telephone: (913) 469-8900.

Ring Chromosome 13

We are the parents of an adorable, 23-month-old little girl who has Ring Chromosome 13 Syndrome. She has microcephaly, a seizure disorder, left-sided hemiparesis, and is small for her age. She was born full term and weighed only three pounds, fifteen ounces, but was not diagnosed until she was four and a half months because her syndrome is so rare. Her syndrome is genetic. Her 13th chromosome is missing a piece and has formed a ring. She does not walk yet, though she is making strides in this area. She "babbles" baby talk and is very cuddly and lovable. We adore her! We also have two other children, boys four-and-a-half and four-months old. They do not have the syndrome.

We would be very interested in being in touch with other families who have a family member with this syndrome. We would also appreciate any information that anyone could recommend regarding this syndrome, as it has been very hard to get any. We are contacting some other organizations which were recommended by NORD and hope that they will be able to offer more.

Our daughter could also have had a number of other major medical problems but, luckily, has been

cleared of them. She is basically healthy, happy and sweet. We have not yet been able to find anyone else with this syndrome and would love to hear from other parents. Thank you!

D.W. & K.W.
Massachusetts

Multiple Congenital Anomalies

My three-and-a-half-year-old son has been "diagnosed" with multiple congenital anomalies.

Shawn developed nystagmus at four months of age and seizures around 18 months. He has short fingers—especially the thumbs—is tactile-defensive and does not talk. He can crawl and use a walker with assistance. During the day he goes to a school for toddlers with multiple challenges.

I have been told that compared to the MRI done at nine months, the one done just recently shows that his brain is slightly smaller.

Not knowing what is going to happen next is stressful. I would like to communicate with parents whose child seems similar.

K.M.
Maine

Editor's Note: There is one Parent Training and Information Center in Maine. Call for help connecting with parents who have a child with a similar disability.

- Special Needs Parent Information Network (SPIN), P.O. Box 2067, August, ME 04338-2067; telephone: (207) 582-2504, (800) 325-SPIN.

Family Support, including Parents Search and Respond is an opportunity for our readers to exchange information about their practical experience meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether letter is a search or response. If a response, please be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters: some are published in **Parents Respond**.

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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD) 100 Rt 37, P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518. Also, see **Exceptional Parent's Annual Directory of National Organizations, 1993-1994**, published in the September 1993 issue.

Parent's Respond

Large Diapers

G.M.F. (June 1993) was searching for a "pull-up" style diaper that would be appropriate for a child weighing more than 50 pounds.

I have the solution! My son is an autistic/mentally retarded 12-year-old and is still incontinent although he is making progress. For five years, I have used Nikky All-Night Pants (all the time). They pull on like regular underpants and contain an all-cotton center padding that holds about one cup of liquid. They come as small as size 3 (34 lbs.) up to 14/15 (93-110 lbs.). Ross still wears the 10/11 size because he is very slender. They are machine washable and dryable on the gentle cycle. The outer shell is made of Nikky's patented, 100% cotton, waterproof material. These are absolutely wonderful! My current source for this "underwear" is Baby Works, 11725 NW West Road, Portland, OR 97229, 1-800-422-2910 or (503) 645-4349.

Other readers may know of more stores that carry them. I discovered a Nikky's advertisement in—guess where—*Exceptional Parent* (in an issue about incontinence products). Thanks bunches! A word of advice: turn them inside-out before washing. They take a long time to dry so purchase at least three pairs. A price break usually accompanies an order of three or more. Good luck!

C.M.
Texas

Durable Clothing

N.D.P. (June 1993) was seeking clothing that would stand up to a 2-year-old who shreds his clothes—even denim jeans—when frustrated.

Our six-year-old autistic son is also quite destructive, both to clothing and to furniture. At one point, Jason went through five clothing items (including denim) in a day, and could pick a mattress clean in an afternoon! His shredding appears to be sometimes due to frustration and other times for sensory stimulation.

After a lengthy search for durable clothing and furniture, we developed our own source. Through a friend, we contacted a man who makes custom boat covers. His fabrics and equipment are very durable, and he has, to date, made a mattress cover, a bean bag chair and two special suits. The suits are one-piece jumpsuits, designed to fit over Jason's clothing, with a strong velcro closing in the back. The front side is doubled and quilted with strips of woven strap material every few inches. We use these suits primarily when Jason is alone in his room, but also, at exceptionally destructive times, in the backyard and car. Although the suit is brightly colored and cute, it does not look like ordinary clothing, so Jason doesn't wear it in public. I'm not sure if this will meet your son's needs but maybe it will give you some ideas for creative sources (maybe an upholstery shop could also help). Good luck—I know how frustrating this problem can be! And if you find any good clothing sources, please let me know!

R.L.
Colorado

Lissencephaly

M.L.B. (June 1993) wrote about her 11-month-old daughter who had been recently diagnosed with lissencephaly: "My problem is that I don't know what to expect from her. Is it true that her life expectancy is three years? She is a joy to be around, but how do you handle the day-to-day living knowing that this could be your last day with this precious gift?"

I am also the parent of a child with lissencephaly. I would like to share my experience with my son that it may bring hope to you.

Joey was diagnosed with lissencephaly at the age of six months. Medical literature states a life expectancy of three to four years. Joey is now 12 years old.

He is a loving, responsive, extremely sociable child—offering a hug to anyone within reach. He is

able to sit, crawl, laugh, clap his hands to music, babble, sing—all things medical literature says he shouldn't be able to do. Despite his severe handicap, he is a delightful child.

I believe the key to coping with Lissencephaly or any other serious disability is to keep realistic expectations. I accepted early on that Joey would never walk. Imagine how happy I was when he began to crawl. Similarly, we read that children with Lissencephaly were unable to speak.

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- CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, Utah.
- HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, Mass.
- IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, Mass.

True, but Joey babbles and sings when happy and expresses his discontent with body language; he communicates amazingly well, without speech.

There are two problems that most children with Lissencephaly encounter—seizures and difficulty in feeding.

Joey has a severe seizure disorder (Lennox-Gastaut Syndrome) that has been a real challenge. He has been on a multitude of medications, yet he still has 25+ myoclonic/tonic/ atonic/absence seizures per day. These seizures affect his level of alertness. To compensate and to allow him to remain active, he must wear a hockey helmet when playing on the floor at all times. In this way, he can avoid the risk of injury to his face from the forceful falls he takes.

As for feeding, Joey's sucking and swallowing reflexes were poor right from birth. Over the years, he was able to follow a normal diet, with his food cut up into small bite-size pieces. However, at age seven, his feeding skills quickly deteriorated. Suddenly, he refused to eat or drink. We had an extremely difficult year, with meal-times lasting two hours or more. Immediately after a meal, he would choke and vomit and we would have to start all over again. Joey began getting aspiration pneumonias and was frequently hospitalized. We were forced to change him to a liquid diet, then NG tube feedings and finally, in 1988, to a "button" gastronomy.

This has proven to be an excellent solution to Joey's feeding problems. He still gets pneumonias, but they are quickly resolved with antibiotics and without hospitalization. He is well-nourished, and is the height and weight of a normal 12-year-old child.

In closing, I would like to stress that the diagnosis of Lissencephaly is not necessarily a death sentence. There have been dramatic changes in medical technology in recent years. With antibiotics, aspiration pneumonia is not the killer it once was. Feeding difficulties can be managed with alternate methods of nutrition. Seizures are a big problem, but can be treated. Like Joey, Erica may help to rewrite the medical literature. So enjoy her!

And don't forget to take care of

yourself so you can stay physically and mentally strong. Don't put your life on hold. Take a vacation with your husband and two other children. Plan for regular respite from Erica's care. You all deserve it!

L.F.
Montreal, Canada

Optic Nerve Hypoplasia/De Morsier Syndrome

S.A. (July/August 1993) was seeking information on the characteristics of children with optic nerve hypoplasia or De Morsier syndrome.

I do not have the information you are seeking, however, I wanted to be sure you were aware of a book called *Loving Rachel* by Jane Bernstein. This book was published in 1988 and is available in paperback. Rachel is diagnosed with optic nerve hypoplasia and demonstrates the echolia you mentioned in your letter. The book is excellent and I'm sure you will find it interesting!

B.F.,
Pennsylvania

Angelman Syndrome

A.Z. (July/August 1993) was seeking information on the heritability of Angelman syndrome.

I have received information on Angelman syndrome (AS) as I needed to rule out that disorder for my seven-year-old daughter who has now obtained a diagnosis of Rett Syndrome. Both are classified as genetic disorders.

An informative booklet called *Facts about Angelman Syndrome* summarizes the history of AS, the genetic framework of AS, and special problems for individuals with this disorder. The AS Foundation strongly encourages each family to obtain genetic counseling to help determine their specific risk for familial recurrence.

You can obtain a booklet from Angelman Syndrome Foundation c/o Jill Hendrickson, 5950-77 SW 20 Ave., Gainesville, FL 32607-3644, (904) 332-3303. This is a very helpful organization for families and professionals dealing with AS.

L.S.
California

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Tracheostomy

B.O. (April/May 1993) wanted to talk with other parents or professionals who'd had experience with children who were trached primarily to facilitate breathing while asleep.

I have a two-year-old who has been on BIPAP/CPAP since September, 1992. The BIPAP machine we use is made by Respironics, 1001 Murry Ridge Drive, Murryville, PA 15668-8550, 1-800-345-6443.

If you write or call the company, they will send you and your doctor

specific information on CPAP or BIPAP for children. Also, look for a sleep disorders clinic in your area.

*P.H.
Minnesota*

Drama Programs for Children with Disabilities

S.H. (April/May 1993) wanted to find drama programs for children with disabilities.

My grandson is a Down syndrome child. He is only a year and a half old so I have no program to tell you

about, but I am a retired senior high drama coach. I have been using Readers Theatre with great success for many years. I have used it with above-average seniors, below-average ninth graders, at camp, in church and with fourth graders. I am sure some of it will work with my grandson and I intend to try. I think it might be something for you to look into.

*N.D.
Pennsylvania*

Awareness Activities for Kids

A.H. (June 1993), a twelve-year-old sibling of a child with ADD, hopes to start a club at school to encourage the acceptance of kids with disabilities. A.H. was seeking readers' suggestions for club activities.

I would encourage any activity that includes both children with disabilities and children without disabilities. When people have the opportunity to interact, they begin to understand each other better. Also, talk openly about what the person with a disability can do, and answer questions that other children may have. I had to wear a body cast for seven months in high school. During that time, some friends stopped asking me to do things. I later found out that some were afraid to ask because they weren't sure what I could do with my cast. Talking about it helped them to feel better and also helped me not to feel like an outsider.

You may also write to Uncle Bear's Book Service at 55 Glenwood Drive in Westerville, OH, 43081, (614) 882-7065. Ask for their catalog. It has a list of books for children on a variety of topics and tells you what age the book is written for. You may work with your school library to obtain some of these books or have a time when teachers and children, a group of children, or children and their families can read these books together. It should open up a lot of discussion.

Lastly, you may consider getting a parent or an adult advisor for your club. They can answer some of the tough questions that you may not have the answer for. When teaching other children about children with disabilities, it is important to give infor-

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mation that is correct. Good luck! I think it's a wonderful thing you are going to do.

C.W.
Ohio

PDHC and Experimental Drugs

J.K. (July/August 1993) wrote searching for other parents of children with pyruvate dehydrogenase complex deficiency (PDHC), especially those with experience with experimental drugs.

My daughter is on Coenzyme Q, Biotrin, Carnitor, Thiamine, Riboflavin and Artane. Her diagnosis is Leigh's Disease or Mitochondria Encephalomyopathy. We do not know if she is missing Pyruvate Dehydrogenase Enzyme or Cytochrome Oxidase C Enzyme as her skin fibroblast were normal.

She is hyponic in her trunk and neck and has significant dystonia (high involuntary movement) in her extremities. She is non-verbal and non-ambulatory. Her presentation clinically was nystagmus at 15 months with continued loss of physical skills.

We recently attempted to take her off the Coenzyme Q because her physician had read a recent article suggesting it had no benefit. We did see a phepecal change and our daughter is back on the Coenzyme Q.

There are three organizations you should be aware of regarding metabolic diseases in children. They will be an excellent resource to you concerning the disorder and its treatment. Also, you will gain wonderful networking opportunities with other families with children with metabolic diseases: 1) National Leigh's Disease Foundation, 601 Taylor Street, P.O. Box 2222, Corinth, Mississippi 38834. They may be able to help you find a doctor knowledgeable in PDHC; 2) Research Trust for Metabolic Diseases in Children (Information and Family Networking): Golden Gates Lodge, Weslon Road, Crewe CW1 1XN, United Kingdom; Tel: 011-44-270-250-221; 3) Muscular Dystrophy Association. There are many chapters in California. MDA covers metabolic diseases of the muscle. They can help support medical treatment.

I wish you well and would be

happy to speak with you. I am a member of the first organization and am a support parent in both others.

L.S.
Massachusetts

Pen Pal

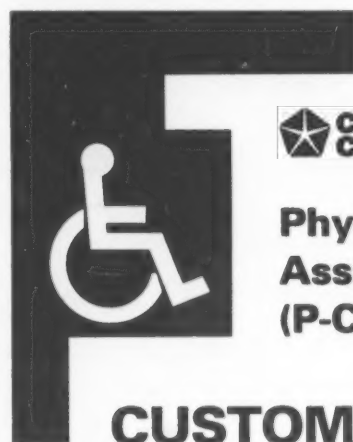
A.P. (July/August 1993) is an 10-year-old boy with cerebral palsy who wrote seeking pen pals.

Hi! I'm a 10-year-old boy in the 5th grade. I have cerebral palsy. I like music, Nintendo and history. I

found out about you from my mother. She showed me your letter. I want to be a pen pal.

I use a computer. I'm in a mainstream class at Glenview Elementary. I have visual impairments and speech disabilities. I am also gifted and cute.

This summer I went to summer camp in Malibu for the blind and visually impaired. And I went to Disneyland. I went up to Oregon and visited some friends. I went to the Jewish Community Center day camp for able-bodied kids. They were too rowdy.



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I'm interested in knowing other kids with cerebral palsy. Please write back.

Your soon-to-be friend,

J.L.B.
California

Cerebella Hypoplasia

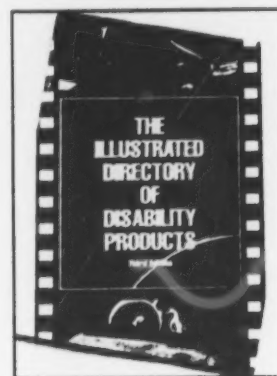
I'm writing in response to J.K. (September, 1993). I have a four-and-a-half year old son, Wesley, who has also been diagnosed with Cerebellar Hypoplasia. His development seemed normal until the age of seven months when I noticed his balance seemed unstable. The pediatrician I was seeing was not concerned. I then decided to find another pediatrician who would listen to my concerns. I found one and he agreed that we should do some testing, but also suggested I take Wesley to a neurologist, which I did. Wesley was 21 months old. The tests that were run were a metabolic screen test, a CT scan, and a fragile X chromosome analysis, all showing normal results. The last test to be done was the MRI which showed cerebellar and midline structure hypoplasia.

Wesley's development also has been slow, but very progressive. Wesley can walk but is extremely ataxic once he is in the upright position and often staggers backwards before he is able to go forward. He can get up to the standing position independently. He never did really crawl. He used a bear crawl (creeping on extended arms and legs) to get around. Wesley also has been wearing glasses for about three years. We were referred to a diagnostic program and school which he attended for three years.

Wesley is now in a program through our local school. It's a PPI (Pre-Primary Impaired) program. He goes to school Monday through Thursday, from 12:55 pm until 2:55 pm. He really enjoys it! There Wesley sees a physical therapist and speech therapist. We have seen wonderful progress in the past three years.

I would be interested in corresponding with you and also hearing if you have heard from other parents who have children with the same diagnosis.

J.T.
Michigan



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The new 1993 *Illustrated Directory of Disability Products* empowers parents and persons with disabilities by widening choices about products.

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CHOOSING HOLIDAY TOYS

The season for exchanging gifts will soon be here. Parents (and relatives) will try to select appropriate gifts for all their children from a vast array of possibilities. While there can be special considerations because of a child's disability, the child with a disability is a child first. Children with disabilities are likely to enjoy the same toys and games as their peers as long as they are able to use them. Nonetheless, finding appropriate toys and games for children with disabilities can be a major challenge for parents and relatives.

This article is about fun gifts, not necessities like clothing or luxuries like portable television sets. While necessities and luxuries can be appropriate gifts for children or adults, we will not discuss such purchases. The focus of this article is fun.

Fun gifts include materials—such as board games—that require (and hopefully, invite) the participation of others and gifts that provide the child with ways to have fun by himself—such as craft activities. Some gifts may serve both purposes. If the toy or game is meant to be used by more than one child, parents need to consider the number of players needed and select toys or games that will be appropriate and interesting for all the children (or adults) involved.

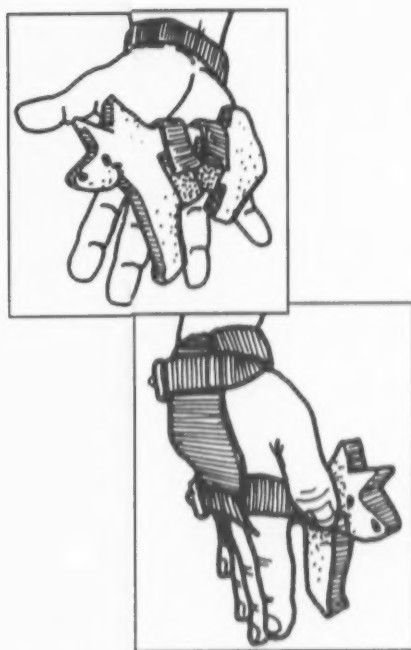
In a short walk through a nearby department store, discount store, or toy store parents will find a wide variety of toys—all sizes, shapes, materials and prices. Some will be familiar ones that we may remember fondly from our own childhoods. Others will be new and unfamiliar. Some may make parents wish that they were children again, while others will make them think wistfully of the "old days" when things seemed simpler. Do not be tricked by contemporary names; many items with modern names are actually old-time favorites that have simply been repackaged.

Today, all parents must contend with powerful television advertisements and print media promotions that are aimed directly at children. Children's toy requests are heavily influenced by this barrage of advertising. It takes time for children to appreciate what parents have learned from experience as shoppers: some toys are as great as the commercials make them appear, but many are not and most seem over-priced.

"Appropriate" gifts

Parents try to respect their children's interests and desires when they purchase gifts. At the same time, parents want to choose gifts that are appropriate for an individual child in a particular family. Parents need to consider the child's ideas as well as their own. Children's interests—especially when they are very young—are likely to be short-lived. Children are also highly suggestible and may change their interests in an effort to imitate siblings or adults. Since the child's range of interests is likely to be fairly fluid at any given time, parents can introduce new material that the child will find interesting.

Young children are usually unable to make realistic judgments about how their interests fit in with the rest of the family. A child may really want a drum when the family places a high value on peace and quiet. Another child may long for finger paints or similar materials that are likely to be very messy, in a household where neatness and cleanliness are important. Thus, while parents



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want to respect their child's interests and wishes, it is important that they also consider their own standards to be sure that the gifts they purchase will be welcomed by the rest of the family.

Similar principles apply to the purchase of games in which parents will be expected to participate. If parents shudder at the thought of playing a particular game because they think it is repetitive or boring, it is best to buy another that will be more appealing to all players. Children are also unlikely to appreciate realistic constraints like necessary play space or needs for storage space. Thus, a child in a mid-town apartment may "really want a pony."

Quality, Safety and Cost

Safety, quality of materials and cost are not major concerns of children. Despite media attention to issues of toy quality and safety, in the pressure and rush of holiday times, these factors are sometimes neglected.

When a child puts almost everything in his mouth, parents try to avoid toys or games that include parts that are sharp, poisonous, or can easily be broken into small, sharp-edged pieces. Toys made of softer, more flexible plastic or cloth are not only more durable; they are much safer. While most parents are mindful of the need to avoid toys or games with pieces that can easily be swallowed, they may forget that small batteries are a component of many larger modern toys. Be sure that battery compartments are secure. From a safety point of view, battery compartments that are difficult to locate and open are ideal.

For any child, but especially a child with poor coordination, parents must be watchful for sharp edges, loose parts and other signs of poor quality. If a child is both poorly coordinated and tends to put things in his mouth, it is even more important to be sure that toys will not come apart easily. If your child throws things, including toys, this becomes a problem in terms of the survival of the toy (as well as the survival of other items and people within striking range). In all of these cases, it is necessary for parents to predict how an individual child is likely to react to a given toy, and then to consider ways to deal with those aspects of the toys that are likely to cause problems.

Costs are important, but higher cost doesn't necessarily mean better quality. Most adults have had the experience of spending a lot of money for a toy or game that ends up being used only once or twice. If a toy is expected to last, paying extra for durability can be a worthwhile investment. Some expensive items, however—like fancy doll house furniture—seem to be made for adults and museums, but not for many children. Essentially, parents need to consider how and where a youngster and his brothers and sisters and friends are likely to use the gift.

It can be especially useful to consider specialty or uncommon items when a child has had a difficult time with ordinary toys or games. Not only will the child have a chance to succeed but other children may be more interested in a novel activity.

Despite parental hints and direct suggestions, children are likely to want something useless, even "terrible." Although parents do not need to purchase such items, they do want to help their children to become informed consumers and make appropriate purchase decisions. Accordingly, parents may sometimes "give in" to pressure to purchase a toy while sharing their concerns about the item with the child.

Toys that "fit"

Children may be clear about their interests but unrealistic about their ability to master the materials. It helps to consider the child's experience in the neighborhood or at school. She or he may have already tried and enjoyed a certain toy. Also, when time permits, it pays to experiment with similar materials borrowed from others or from a toy library.

Along with considering a child's abilities, it is important to think about the environment in which a child will use a toy or game. Space is an important consideration. For example, will the toy fit easily on a wheelchair tray or bed tray? Does it need to be used on a table or on the floor? When a game is set up, can the child easily reach all of its parts?

One dilemma parents face in choosing gifts is whether to pick materials that they know their children can use and enjoy or whether they should choose at least a few gifts that might have some degree of therapeutic value by providing the child with experiences in areas in which he is limited. Such gifts can have a gnawing appeal to parents because they look like materials that might be helpful in solving a problem.

At holiday time, however, fun should be the major criterion for selecting gifts. The hoped-for educational and therapeutic value of a toy or game calls for careful consideration. The label "educational" (or "therapeutic") may be attached to materials for children simply to increase sales potential. In fact, most toys and games can be considered "educational" because they teach such essential skills as waiting one's turn, playing by the rules, counting, or following directions.

Parents can consult with professionals who know their child whenever they are tempted to purchase materials that supposedly have educational or therapeutic value. Teachers and occupational therapists can be especially helpful because they often know how to use many different, commonplace materials in an educational or therapeutic manner.



One Man Band adapted toy moves about and makes music; requires switch and batteries. Jesana Limited.

Parents want to select a toy or game that "fits" the child for whom it is intended. Manufacturers' age-level recommendations tend to be relatively poor guidelines to use when buying toys for a child with special needs. At the same time, a child may be put off by a toy that is too easy as well as one that is too hard. Children usually are eager to work towards goals that they perceive as attainable. It can be a delicate balancing act to find a toy challenging enough to hold a child's interest, but not so difficult that it leads to frustration and failure.

At first glance, many toys and games may appear to require thinking, memory or fine motor abilities that are beyond a specific child. Materials or instructions may initially appear daunting. However, creative parents and professionals have developed many flexible adaptations that allow children with complicated disabilities to utilize everyday playthings. The play materials need to be adapted, but the adaptations will not diminish a child's enjoyment of the toy.

Various aspects of games can be adapted. Many board games require the ability to move a small object from space to space across the playing surface. Markers may be made heavier or larger. The playing surface may be attached to a turntable to make it easier to get to the board or it may be mounted on a piece

of wood so that holes can be drilled in each of the spaces of the game. Then markers can be attached to golf tees or small dowels that fit in the holes so a child can move them from space to space without losing count or upsetting the board.

Card games and other table games can also be adapted with the use of magnetic boards or special devices to help grasp the cards or dominoes.

Many typical toys can be adapted. Relatively simple modifications like a Velcro® mitt may help a child grasp toys or game pieces. Similarly, a non-slip material can be glued to the bottom of lightweight checkers to keep them from sliding around the board.

Rules for participation are also adaptable. It is unfair to expect young children to remember intricate rules or even be particularly concerned about following them. Parents can create simplified rules initially. A memory game, for instance, may be made easier by using fewer pairs of cards or more difficult by using more. Many toys can be played with in more than one way. Dominoes, for example, can be played as a game with other children or used as a building set.

While this article has emphasized toys and games, books, records and tapes, and pets can also be exciting gifts. Books can be fine gifts even when a child is intellectually limited. Children of all ages enjoy being read to, especially by adults. Today, many children's books have been rewritten as high-



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interest, low-vocabulary versions so even children with limited reading skills can enjoy interesting stories. Librarians are excellent resources for recommendations of high-interest, low-vocabulary books. Librarians can also direct parents to children's books dealing with disability related issues.

Audiotapes and videotapes are also popular gifts—especially if they invite interaction and participation with others. Earphones may become important when parents lose interest in repeat performances.

Most children look forward to pets without completely appreciating the time and energy necessary for proper care. Here, experienced parents suggest starting with creatures requiring minimal care.



Customized Activity Boxes provide sensory interaction for children with impairments of vision, hearing or both. Jesana Limited

child is able to handle the controls.

School-age children usually enjoy the thrill of making things for themselves or as gifts for others—jewelry, collages, scrapbooks, models, etc. Such common childhood activities can be difficult for children with disabilities because they may be unable to read the instructions or handle the fine detail work because they cannot perceive the materials or coordinate their fingers with the necessary dexterity. By visiting a craft shop and being imaginative or talking with an occupational therapist or art therapist parents can discover ways in which they can alter the available materials so their child can succeed. For some activities, it may be necessary for a parent to work closely with the child. If so, parents can try to encourage the child to do as much as she can do on her own.

Active rather than passive

Toys, games and other materials that give the child an opportunity to be active are better than materials that require only relatively passive observation or listening. This is particularly important for children with limited mobility. Electronic games can be great fun as long as the

Catalog purchases

Busy parents often find mail order catalogs helpful for shopping. Be sure to ask about the company's return policy in case you are dissatisfied, the item doesn't work properly or it turns out to be inappropriate. Also verify whether

continued on page 55

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A FINE PURPOSE

by Carol Abbott

Years ago, when I was desperately searching for meaning and hope after hearing the devastating news about the severity of our son's handicaps, Exceptional Parent magazine became my friend. I was ready for the next issue as soon as I put down the last, and avidly read each letter and article as if it were meant just for me. I learned a lot from your writers—parents who had been there before me.

In hopes of returning some of the encouragement and hope that I found in your pages, I wrote this article to express the positive aspects of our experiences as parents of an exceptional child.



The entire restaurant seemed filled with a shared excitement as we waited for the long-planned moment. Then, on cue, the glowing light of 80 candles greeted us as Grandmother's cake was carried into the room. Everyone joined in singing a rousing chorus of Happy Birthday. And then it happened—Brian began *laughing*. His smile was brighter than the collective glow of the candles; his giggle captivated every person in our group. We faltered in amazement—Brian was laughing!!

Three and one-half years had passed since his birth and the crushing news—he had severe brain damage of unknown origin. Surely the diagnosis was a mistake! These things don't happen to people like us. Yet our own eyes could not deny that something was wrong. He didn't look at us. He didn't eat. His cry sounded... strange. Slowly, the wrenching grief known by all parents of children with disabilities fell like a blanket over our world. We mourned for our dream child who had seemingly died. We mourned the death of our dreams—for the smiles that didn't come at two months, for the sleep that still hadn't come at 12 months, for sitting in doctors' offices instead of playing in the sun. Oh, so many reasons to grieve!

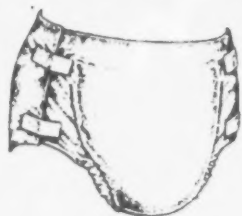
My worst moments came when it was my night "on." Brian had an undiagnosed seizure disorder, and he "startled" awake nearly as soon as he drifted to sleep. As a result, we spent two years alternating nights "on duty," walking him back to sleep and napping with him on our chests.

During those horrible nights, I would cry out to God. I demanded to know why we were being tormented in spite

Above: Brian, age 3 1/2, enjoying Christmas cheer.

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of our prayers. I felt sorry for myself, for my husband, Jay, and for Brian. It seemed horribly unfair that Jay and I should be punished with such terrible grief. It seemed worse yet that our beautiful little son should be so horribly contorted and limited by cerebral palsy.

In a nutshell, I was angry at God. Why should parents like us, who cared so deeply, be spending so much of our creative energy taking care of a child who would never contribute to society? This was my silent horror. I had been raised with a strong belief in "giving something back" to society. Now it appeared that I would spend the rest of my days taking care of someone who would never give anything back to anybody. The guilt I felt over such disloyal thoughts about my innocent son compounded the pain.

With the birth of Brian's new sister, Katy, I nagged God even more persistently—demanding answers, healing, anything. At a very early age, Katy showed every sign of being "gifted"—reciting the ABCs before other children her age could even talk, "reading" every book she could grab with her chubby little fingers, and charming the socks off everyone she met. As I watched her and envisioned her making her way through school, I was struck by the inequities: Brian would always get far more help than Katy would. His education would always cost far more than hers. Would he ever even know or enjoy all the extra care he was getting?

My questions changed little in the routine of our daily lives. Brian "improved" (in disposition, at least) and began responding to our meticulous, if not always joyfully given, care. He began school and seemed happy. He was a very beautiful child and his newly found smile—especially when he heard whistles, bells, or our sing-song "Hello, Brian"—would light up a room. As he grew, Brian continued to amaze us with his patience, loving spirit and sweet nature. Though he had been a very cranky baby, he now endured many surgeries for hip displacement, gastrostomy (feeding) tubes and tooth caps with almost no complaint. We learned to love him deeply, and took delight in his constant attempts to engage us with his smiles and giggles.

What was most remarkable was Brian's effect on other people. Beginning with his first care provider and continuing with every baby-sitter, bus driver and professional he met, he built a loyal following. As proud parents, we basked in the love people showered on him but we were always a bit puzzled. How could he have such a way with people when he couldn't talk, walk, reach out and touch them or—with his limited vision—even look at them?

Yet it was universal. Brian touched people in a way that was quite astonishing. Those who became close family friends were almost as puzzled by it as we were. They attempted to explain his impact by saying things like "He just has a special way about him" or "He's just a little angel." Without knowing what he did or how he did it, to a person they found that they were moved and changed for the better by their encounters with Brian.

On one level, he helped people gain a new perspective on their own troubles and start enjoying life. After all, if this little boy could be trapped inside a totally dysfunctional body, yet remain so sweet and happy, how could they complain about their troubles? You could almost hear them thinking, "And I thought I was having a bad day?"

On another level, people were simply impressed with his *being*. Brian radiated a peaceful acceptance of life

The doctors who had diagnosed his cerebral palsy when he was young told us that he would be very profoundly retarded, but few who knew him could believe that he was. He had a way of communicating his understanding and acceptance. He was a charmer without any artifice of manipulation.

Without any warning, Brian died peacefully in his sleep before his sixth birthday. We were shocked; he had been so healthy just the day before when all of us had been together at church to see his sister Katy "perform" for the first time in the toddler choir. Grandma and Grandpa had been there along with the entourage of his friends who never failed to greet and talk to him at church.

Now, once more, we mourn the death of our son. Oh, to hold him again! Oh, to have his sweet smile greet me in the morning or to hear his delightful giggle when we sing! The depth of missing him takes my breath away and wakes me with tears in the night, but strangely, this time the grief is less desolate. Brian, who radiated such a beautiful spirit, is free at last from that torturous, uncooperative body. As his sister said, he is finally able to sing and dance his heart out as a little angel.

What irony that he should die when we had become so comfortable with the reality of our "different" life and family! What irony that he should die when his dad and I had finally accepted his disabilities—to the point of remodeling the house to fit his needs and planning our finances

Carol prepares to take two-year-old Katy and four-year-old Brian for a bicycle ride.



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and future with Brian in mind.

Or was it ironic? We have come to believe that Brian couldn't leave us until we *had* accepted his disability; until we *had* completed our grieving and reached a peaceful, even joyous acceptance of our life with him *and* his disability. We had incorporated Brian so fully into our life that we even spent a week tent-camping with him at our church retreat—no small feat with gastrostomy feedings and still-frequent vomiting! It was a beautiful experience that deepened our faith in God and strengthened our bonds as a family.

His purpose? I have no doubt that he had one—and a fine purpose it was! As testimony to that, over 300 people attended his memorial service, wrote cards and came by our home to tell us how moved they had been by his presence. Many of them were "strangers"—people from church we had not yet met. They struggled to find words to express the ways Brian had touched their lives. Their tears, and the love they had shared with him when he lived, spoke volumes about Brian's impact.

Brian taught Jay and I how to enjoy each moment, how to accept what is given and live fully. He taught our families and friends how to give unconditional love, and how to see the essence of a person's soul without the trappings of success, talent or achievements. He taught our neighbors and co-workers how to count their blessings and

Above: One-year-old Brian goes for a swim with Grandma Mollie.

Below: Christmas 1988: 20-month-old Brian with his new sister, Katy.

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566

be thankful for what they have. He taught all of us how to experience God's love and grace even in seemingly miserable conditions.

I have a new perspective on what it means to contribute to society—thanks to a little boy who could not walk, talk, write, sing, play or draw. He contributed his being, and all of us who were blessed by knowing him are richer by far for the experience. ■

Carol Abbot is an educational consultant and former elementary school teacher who lives in Sacramento, California with her husband Jay and daughter Katy. Both Jay and Carol continue to serve on the board of their local support group, Parents for Special Children. Carol works part time in order to spend as much time as possible with Katy, who just entered kindergarten.

We wrote this to thank people for their help after Brian's death. We recently heard that a four-year-old girl and a one-year-old boy are now healthy after receiving transplanted valves from Brian's heart. We are gratified to know that Brian's contributions to the lives of others are now physical as well as spiritual and emotional.

Our Thanks

Brian's life taught us so much.

We learned to be patient—

he was patient in spite of great pain.

He taught us love beyond measure—

love we had no idea we were capable of feeling.

And Brian served as a bright mirror—

reflecting for each one of us our own best nature.

For these blessings, and for his beautiful smile,
we are ever grateful, and will miss his presence daily.

Brian's death was also a great teacher.

In spite of the deep sorrow, we learned joy—

the joy of his release from pain into God's grace,

and the joy of realizing the power of love

in the human community.

Friends, family, co-workers, church and Brian's helpers—

each gave, unbidden, your love, support and comfort.

But the greatest of gifts that you gave is still with you.

May we all learn to give to each other, every day,
some of the immeasurable grace shown to us by God.

Carol, Jay and Katy Abbot

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Health Care Reform:

by William Sciarillo, Executive Director, ACCH

The process of reforming the country's health care system—a current focus of the Clinton White House—offers a short-lived window of opportunity for effecting long-term changes in services for children with disabilities and chronic illnesses. Advocates for children with special needs are taking advantage of every chance they get to make sure that the administration is aware of the unique health care challenges faced by these children and their families.

The administration is listening

In April, I represented the Association for the Care of Children's Health (ACCH) at a White House briefing on health care reform as it relates to children and youth. Other key organizations and programs, such as the Children's Defense Fund and the Association for Maternal and Child Health Programs, were also represented. At the briefing, members of the Administration's Health Care Task Force tried to provide us with "a sense of where this thing is going," then listened to our responses and suggestions.

Task force members emphasized the Clinton administration's commitment to assuring a comprehensive benefits package for all children while recognizing that a single benefit package will not be appropriate for every child. For example, some children may need additional services such as outreach, health care coordination and transportation. Task force representatives stressed that service financing and delivery must be "sensitive to the changing needs of children with special health care needs and disabilities." And, for the first time since the beginning of my involvement in the health care reform process, I heard an administration representative use the term "family involvement."

Basic benefits for all

As envisioned by the Clinton administration, health care reform should address issues of universal access, basic benefits, integrated service delivery, public accountability, medical liability reform, administrative cost reduction and anti-trust considerations. As anticipated, task force members describe "managed competition" as the basic framework for the developing plan. Managed competition involves the organization of the health care coverage system into "Health



Photos courtesy of (left) Arkansas Children's Hospital, Little Rock, Arkansas. Photographer: Kelly Quinn. (right) Santa Rosa Health Center, San Antonio, Texas. Photographer: Joan Snow. Photos displayed at the ACCH/NACHRI 1993 Capitol Hill Photo Exhibit

563

Getting to the Heart of the Matter

Alliances" and "Accountable Health Plans." Health Alliances are "super-sized purchasing cooperatives" which will represent large, diverse groups of enrollees in buying health insurance from Accountable Health Plans or "super-sized HMOs." This system would link large numbers of individuals with networks of nearby medical facilities and providers. All health care plans would be required to offer a basic benefits package, with individuals having the opportunity to purchase benefits beyond this standard package. Certain special needs groups (e.g., children with disabilities) may qualify for a "long-term and community-based care benefit."

While it is clear that the Clinton plan will go far beyond previous attempts to simply "fine-tune" the health care system, the degree to which it will comprehensively address the needs of children with disabilities or chronic ill-

nesses remains to be seen. Will the national benefits package provide for ongoing medical and developmental specialty needs such as physical therapy, occupational therapy, speech therapy and assistive devices? Will it allow for related family support services such as counseling, care coordination and transportation?

Working out the details

While the broad outline for reform receives widespread media coverage, parents, providers and advocates need to focus on the details that are relevant to children with special needs. Last April, I left the White House briefing with a gratifying sense that our concerns had been heard. But being heard is not enough. Some fundamental issues related to the needs of children with disabilities and chronic illnesses will require continual advocacy as the President's



plan makes its way through Congress. The recent legislative defeat of President Clinton's first Childhood Immunization Initiative demonstrates that even obviously cost-effective children's health measures can be sacrificed to politics.

Most advocacy groups agree on the basic components necessary to a comprehensive health care plan to meet the needs of children with special needs and their families. ACCH has taken the position that health care reform must address the comprehensiveness and quality of services provided—beyond purely medical or technical aspects of care. We are advocating for a family-centered approach to care that addresses the developmental and psychosocial needs of children and fosters parent-professional collaboration at all levels, ranging from the care of an individual child to program development evaluation and policy formation. (A copy of *Key Elements of Family-Centered Care*, developed by ACCH's National Center for Family-Centered Care, is available through ACCH at no cost. Send a stamped, self-addressed envelope to: ACCH NCFCC, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814.)

Family Voices, a national coalition of families of children with special needs, takes a similar position in calling for universal access, flexibility, comprehensive, coordinated community-based care, family-professional partnerships and an emphasis on the value of families within the health

care system. (For more information about Family Voices write c/o P.O. Box 769, Algodones, NM 87001.)

PRINCIPLES TO GUIDE REFORM

The National Maternal and Child Health Coalition—uniting such groups as the Association for the Care of Children's Health, Children's Defense Fund, March of Dimes Birth Defects Foundation, National Association of Child Advocates, National Association of Children's Hospitals and Related Institutions, National Association of Developmental Disabilities Councils, National Easter Seal Society and National PTA—has developed *Principles for Maternal and Child Health Care Reform*. With respect to children with special needs, these principles call for the President's health care plan to:

- prohibit pre-existing condition exclusions and waiting periods;
- provide access to comprehensive services equivalent to those now available under Medicaid's Early Periodic Screening, Diagnosis and Treatment Program (EPSDT), covering a wide array of medical, developmental, and related support services;
- assure additional services such as case management, transportation, and home visits for certain groups;

- prohibit benefit caps which discriminate against children with special needs;

- provide resources for developing and maintaining quality specialty services for children with special needs;

- commit to the recruitment, training, placement, and retention of primary care providers and specialists to care for children with special needs;

- institute a system of needs assessment, quality assurance, and development and distribution of resources that provides for consumer input and review;

- prevent plans from shifting costs to families, particularly those with low incomes;

- ensure the continuation of a full range of services to those now eligible under federally mandated programs such as Medicaid, until coverage is completely phased in under the new plan.

Any health reform package to emerge from the legislative process should be measured against the positions of these advocacy groups.

Photo courtesy of Mt. Washington Pediatric Hospital, Inc. and Mt. Washington Pediatric Home and Community Care, Inc., Baltimore, MD. Photographer: Joe Rubino.



TOILET SUPPORT NEEDED

A large base of grassroots advocacy support is necessary to ensure that legislators and policymakers are made aware of the need for timely passage of legislation that comprehensively addresses the needs of children and youth, including those with disabilities or chronic illnesses. Here are some important things that each of us can do:

1. *Contact legislators.* Make sure that your U.S. representative and senators, as well as your state legislators, know of your support for health care reform consistent with the principles stated in this article. You can reach the offices of your representative and senators by calling 202-224-3121. You can also state your positions and ask questions at town meetings or other local events, engage in letter writing campaigns and write editorials.

2. *Encourage organizations and groups within your area to support these principles.* You might start with the health care provider that serves your child. To request a sign-on-reply form for the *Principles for Maternal and Child Health Care Reform*, your group may contact the National Association of Child Advocates (NACA), 1625 K Street, Suite 510, Washington, DC 20006.

3. *Contact Family Voices to learn of your state's FV Coordinator or contact your state child advocacy organization* (where one exists) to learn how you may benefit from their expertise and resources, and how they may benefit from your expertise, networks and personal stories (NACA can assist in locating your state organization).

4. *Consider joining an advocacy and education organization* such as ACCH. Membership in an advocacy organization includes you in a collective voice that will make a difference. As an ACCH member, for example, you will have ongoing access to invaluable resources and networks—at the national, state, local, and individual program and hospital levels—that promote health care policies and practices responsive to the needs of children and families. The mutual respect and caring that exists among ACCH multi-disciplinary professionals and family members along with a commitment to quality care across the continuum of disabilities and conditions are our greatest advocacy tools.

Regardless of the health care plan that will eventually be implemented at the national level, real change in the lives of children and families must occur in the states, cities, towns, and communities where they live. It is imperative, therefore, to continue our individual and collective local efforts to improve existing programs for children and families.

Yogi Berra once said, "The future is not what it used to be." He could have been speaking about the challenge we have been given to shape the future of health care in this country. This debate presents an opportunity for each of us to contribute to the future. Perhaps Hillary Rodham Clinton described our mission most aptly in a speech at the recent American Hospital Association's annual meeting—"Health care reform is about reinstituting a sense of compassion and caring into our society." ■

William Sciarillo, Sc.D., has been the executive director of ACCH since 1992. In this capacity, he also serves as project director for several national grants which include the National Center for Family-Centered Care, the Family-Centered HIV Project and the National Information Clearinghouse for Children with Disabilities and Life Threatening Conditions. He resides in Baltimore with his wife, Marycatherine Augustyn and daughter, Emily Sciarillo.

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The Association for the Care of Children's Health is a nonprofit, international education and advocacy organization. ACCH's purpose is to promote policies and practices that meet the comprehensive health, developmental, and emotional-social needs of children and their families. Consistent with ACCH's role as the *National Center for Family-Centered Care*, family members of children with special needs are an important part of all Association activities.

ACCH membership provides a forum for family professional and interdisciplinary interaction, collaboration, and learning through:

- subscription to *The ACCH Advocate*, a new publication launched in Fall 1993 and to the quarterly journal, *Children's Health Care*;
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- membership in one of 30 regional local affiliates;
- and, most importantly, an opportunity to be part of a collective voice that makes a difference!

ACCH provides matching funds for family members of children with special needs through a Caregiver Family Scholarship program. For more information or to join ACCH, call Paul Skoglund, membership manager, at 1-800-229-1350, or write to: ACCH, 7910 Woodmont Avenue Suite 300, Bethesda, MD 20814.



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No Pity

by Joseph P. Shapiro, ©1993
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Never has the world of disabled people changed so fast. Rapid advances in technology, new civil rights protections, a generation of better-educated disabled students out of "mainstreamed" classrooms, a new group consciousness, and political activism mean more disabled people are seeking jobs and greater daily participation in American life. But prejudice, society's low expectations, and an antiquated welfare and social service system frustrate these burgeoning attempts at independence. As a result, the new aspirations of people with disabilities have gone unnoticed and misunderstood by mainstream America. This book attempts to explain, to nondisabled people as well as to many disabled ones, how the world and self-perceptions of disabled people are changing. It looks at the rise of what is called the disability rights movement—the new thinking by disabled people that there is no pity or tragedy in disability, and that it is society's myths, fears, and stereotypes that most make being disabled difficult.

There are hundreds of different disabilities. Some are congenital, most come later in life. Some are progressive, like muscular dystrophy, cystic fibrosis, and some forms of vision and hearing loss. Others, like seizure conditions, are episodic. Multiple sclerosis is episodic and progressive. Some conditions are static, like the loss of a limb. Still others, like cancer and occasionally paralysis, can even go away. Some disabilities are "hid-



den," like epilepsy or diabetes. Disability law also applies to people with perceived disabilities such as obesity or stuttering, which are not disabling but create prejudice and discrimination. Each disability comes in differing degrees of severity. Hearing aids can amplify sounds for most deaf and hard-of-hearing people but do nothing for others. Some people with autism spend their lives in institutions; others graduate from Ivy League schools or reach the top of their professions.

There are some 35 million to 43 million disabled Americans, depending on who does the counting and what disabilities are included. In 1991 the Institute of Medicine, using federal health survey data, came up with a total of 35 million—one of every seven Americans—who have a disability that interferes with daily activities like work or keeping a household. "Disability ranks as the nation's largest public health problem, affecting not only individuals with disabling conditions and their immediate families, but also society at large," the report concludes.

During debate on the Americans with Disabilities Act, law-makers,

President Bush, advocates, and members of the media freely used the higher figure of 43 million. That number came from other federal data. But even this figure did not include people with learning disabilities, some mental illness, those with AIDS, or people who are HIV positive and have other conditions covered under the civil rights legislation. Researchers cannot agree on the size of the disability population because they have no consensus on what constitutes disability.

The disability movement is a mosaic movement for the 1990's. Diversity is its central characteristic. No one leader or organization can claim to speak for all disabled people. It is accepted, as a matter of course, that members of the disability cause will hold shades of belief and not bow to an overriding orthodoxy. All social crusades are made up of people with complex and varying opinions. But today the black civil rights and feminist movements, in particular, are perceived as struggling with such diversity of thought and weakened by challenges to traditional thinking. The result is to diminish our appreciation of the enormous change each cause has brought about. Without one highly visible leader, the disability movement has gone largely unnoticed by nondisabled people. But by its acceptance of differences, the campaign for disability rights has forged a powerful coalition of millions of people with disabilities, their families, and those that work with them. People with disabilities have been a hidden, misunderstood minority, often routinely deprived of the basic life choices that even the most disadvantaged among us take for granted. In the last twenty to thirty years, little noticed alongside the civil rights struggles of African-Americans, women, gays and lesbians, and other minorities, another movement has slowly taken shape to demand for disabled people the fun-

damental rights that have already been granted to all other Americans. It has led to the emergence of a group consciousness, even the start of a disability culture, which did not exist nationally even as recently as the late 1970's.

Helping Children Overcome Learning Difficulties

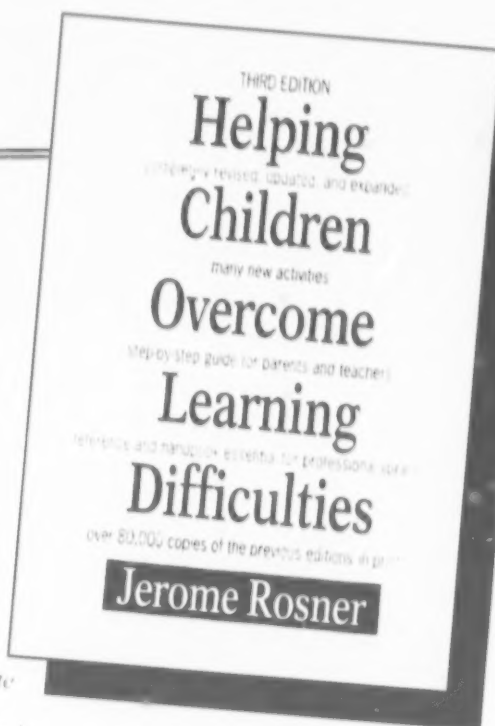
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Children, like adults, differ one from another. None (with the exception perhaps of identical twins) looks exactly like someone else, none has a voice that sounds exactly like someone else, and none of them thinks exactly like someone else. The brain comprises billions of neurons; it is unrealistic to believe that any two brains are exactly alike in structure, organization, and function.

Schools are very much like one another. True, no teacher is exactly like another teacher, but most instructional programs are very much alike (indeed, many schools purchase and use the same instructional programs), most school buildings are organized much the same, and most schools use the same achievement tests (hence, the same instructional goals) that scale the children against national norms.

This book is in part a chronicle of the formation of this movement and the issues and identities that define it. At the same time, I hope to help draw attention to the political and social issues that have yet to be resolved. There is potent and widespread sup-

port for the movement's accomplishments and goals among disabled people, their families, and friends, and even many of the charity and professional groups that are so often the target of the movement's anger, but the struggle is far from over. ■



What happens when an unusually tall child enters a standard first grade classroom and the teacher finds that there are no desks that can accommodate him? She informs someone in the building that she needs a larger desk for this child. She does not feel the need to have a series of consultations and apply a label ("extra tall," perhaps) before she submits her request; the school custodian responds without questions. A larger desk is brought to the classroom and life goes on.

What happens when a left-handed child enters a standard first grade classroom that contains desks for right-handed children only? The teacher—without seeking someone else's opinion and without having a panel of experts testify that the child is truly left-handed—has a left-handed desk brought to her room.

What happens when a six-year-old with immature visual or auditory perceptual skills, or inept language

ability, shows up in a standard first grade classroom? The teacher—usually unaware of the deficits—starts off by attempting to teach this child the standard curriculum in the standard fashion. By midterm, the teacher has become sufficiently frustrated and concerned that (if the school is located in a middle-class neighborhood) she requests conferences with the school diagnostician and the child's parents. (If the school is located in a poor neighborhood, she might simply shrug and accept the situation as not unusual. Isn't that unfortunate?)

During the teacher-parent conference, mention is probably made of possible dyslexia, or attention deficit disorder, or something like that, and the parent is surprised and troubled. This is followed by more tests, conducted in and perhaps out of school, and more conferences. Finally, in the best of cases, the child acquires a label that earns him nonstandard circumstances for all or part of the school day. He is taught in different ways, with the methods decided by the teacher, who was prepared for her job by college instructors who rarely, if ever, have had direct teaching experiences with this kind of child. In even worse cases, the child is simply labeled. The label becomes the reason for his school difficulties, and that is that.

In all cases, the child's school difficulties are *his* problems, not the school's. If he has an idiosyncratic brain, then he must pay the consequences. Indeed, even if special instructional circumstances are provided, the problem remains his and he is expected to overcome it in a reasonable length of time because schools

cannot accommodate idiosyncratic needs forever. After all, "he has to become independent sometime," and "the sooner the better."

Do his teachers expect him to "get better"—to reach a point where he will learn the way "normal" children learn? Some may, but they are rare. Usually the label once attached remains attached, and with it acceptance of the "fact" that this child will endure his problem for life.

This is wrong both in principle and in fact. True, a good number of children enter school unready for the experience, and there is no reason to blame the schools for this. But neither is there reason to blame the child. He did not make the laws that condemned him to this fate, and he did not design the genetic, physiological, and experiential factors that made him what he is.

The job of the elementary school educational process is to teach children the information and skills they will need to perform satisfactorily in secondary school. Within this undertaking, the first major goal of the educational process is to teach the child how to be an accurate and fluent reader, speller, writer, and calculator (how to deal with information in symbolically coded form).

If that goal is achieved "on schedule"—typically, before the end of third grade—then the child has a good chance to go on successfully to intermediate and secondary education and, perhaps, beyond. If that goal is not achieved on schedule, then the child will be behind when he enters fourth grade, and the probabilities are that he will remain behind for the remainder of his school years. In fact, the gap between where he should be and where he is will widen, inevitably causing him frustration leading to anger toward the society that placed him in these circumstances, and toward himself and his failure.

The central theme of this book is that none of this need occur. *If* parents were aware of the importance of preschool development and how it influences early learning, and *if* schools were able and willing to identify and accommodate children who enter school not yet ready for standard conditions, then most of the children who bear the special education

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Developing

by Ruth A. Wilson

As parents of children with special needs, you realize the importance of developing individualized educational plans for your children. What may be less obvious, however, is the importance of developing individualized plans for yourselves. While your son or daughter needs an IEP, parents may need an ILEP, an Individualized Life Enhancement Plan.

Since stress and burnout can create havoc in our lives, the development of an ILEP can be an important first step toward a more personally satisfying way of life.

Needs assessment

Developing an ILEP is not that different from developing an IEP. The basic process is the same. As with an IEP, we start with an assessment of our needs, proceed through identifying appropriate goals and action statements and then establish a plan for evaluation. The first part—determining where you are—is based on a needs assessment of one's personal life. You might ask yourself, "Where am I on the scale of living a personally satisfying life?" Next, examine the various aspects of your life to identify strengths and needs. Think about your physical, social and emotional well-being. The following are some questions you might ask:

Physical: Do I feel vibrant and healthy? Do I feel physically fit? Am I exercising and eating well? Do I give my body enough rest and relaxation?

Social: How often do I get together with friends, or go to movies, concerts or plays? What kind of social life do I have?

Emotional/psychological: Do I like myself? Am I generally satisfied with my life? Am I having fun?

After examining your personal life and determining your strengths and needs, it's time to set priorities. Your needs assessment may have indicated that you rarely exercise, that you're rather disorganized in your work, and that you spend very little time with your friends. If you feel that one or more of these areas plays only a small part in your life, ignore it. The point of the self examination is to identify areas of neglect or need that are important to you.

Goals

Once you identify and prioritize areas of concern, you can make specific plans for changes in your life. This is part two of the ILEP process—the development of goals for

yourself. The goals on your ILEP should be general statements of what you hope to accomplish over a certain period of time. ILEP goals might include "to spend more time with my children," "to spend less time at work" or "to become more socially active." Because an ILEP is intended to enhance the quality of your life, it's important to limit yourself to no more than two or three goals. Trying to concentrate on too many goals at one time will cause frustration and stress rather than feelings of joy and satisfaction.

Part three of the ILEP process involves moving from abstract goals to actual changes in your life by translating your goals to "action statements." These action statements are comparable to the short term objectives on an IEP. They outline the steps you can take right now to make positive changes in your life. For example, if one of your goals is to develop closer friendships, a related action might be to visit, write or call a friend at least once a week.

As with short-term objectives on an IEP, the action statements in part three of your ILEP should be positive, realistic and measurable. Keep these statements positive by focusing on what you want or what you're moving toward. The following examples illustrate the difference between positive and negative statements.

Positive

I'm going to walk 30 minutes during my lunch hour three times a week.

I'm going to get involved in the social committee at church.

I'm going to plan something fun to do with my son at least one evening each week.

Negative

I'm going to stop eating lunch at my desk every day.

I'm going to spend fewer evenings by myself at home.

I'm going to stop fighting with my son over his messy room.

Be realistic

In addition to being positive, your action statements must also be realistic. Even though you may want to take walks during your lunch hour, this may be an unrealistic goal. Perhaps the environment around your home or workplace is not conducive to a relaxing or invigorating walk. If your action statements aren't realistic, you'll only be setting yourself up to fail by trying to work something into your life that doesn't fit. As with your child's IEP, it's far better to

Your Own I(L)EP

have a plan that can be accomplished—even if it moves you only one small step toward a desired goal—than to decide on a plan that sets you up for failure and disappointment.

Keep track of progress

Action statements also need to be measurable. You must be able to objectively gauge whether or not you're making changes in the right direction. Objective measures keep us honest. They can also serve as powerful motivators.

It's important to evaluate progress toward your goals. An evaluation plan should include specific monitoring activities which will be carried out at regular intervals. For example, if one of your goals is to spend more time with your friends and you've decided to contact a friend at least once a week, you may plan to evaluate the past week's progress every Sunday morning.

Write a contract

The last part of the ILEP process is to enter into a written agreement with yourself. In this part you will write a contract promising that you will take definitive steps to take care of yourself. One way to start this statement is as follows: "Because I value myself and believe in living a healthy, balanced life, I will..."

Once you've finalized your ILEP, sign it, date it and celebrate. Do something special for yourself *now*—take a walk in a park, go out to eat with a friend, or spend all afternoon reading a novel.

Now it's time to implement your Individualized Life Enhancement Plan. Investing time and energy in an ILEP can make your life healthier and more satisfying. Children are not the only ones who need an investment of time, energy, and planning in order to accomplish important goals in life. To avoid stress and burnout, parents also need individualized plans for continued growth and joy. ■

Ruth A. Wilson is an assistant professor in the Department of Special Education at Bowling Green State University in Bowling Green, Ohio. She has a master's degree in special education and a doctorate in early childhood education. Dr. Wilson was a special education teacher for 12 years and has worked with students from preschool through graduate school. She lives with her husband, Fred, in Toledo, Ohio. She has two daughters, a step-daughter and a grandson.

1. Where am I now?

I seem to be working all the time. I rarely read a book or go out with friends. I'm getting involved with the parent group at school and find that I'm enjoying it.

2. Where do I want to go?

Goal One: to build more varied and interesting activities into my life.

Goal Two: to get more involved with social activities outside the home.

3. Action statements

- *I will try out for a part in our community theatre.*
- *I will go out for breakfast with a friend every Saturday morning.*

4. Evaluation plan

By March 1st, I'll know whether or not I got a part in the play. On February 1st, I'll check back on my calendar to see if I followed through with my Saturday breakfasts.

5. My solemn promise:

Because I value myself and quality of life, I'm going to take better care of myself and not work all the time.

Signature: *Mary Jane Smith*

Witness: (optional)

Date: *October 25, 1992*

Date to be reviewed: *April 25, 1993*

Comments: *This could be fun and I owe it to myself!*

Sample Individualized Life Enhancement Plan (ILEP)

Health Care Reform— Write Now

Health care reform is a central issue for everyone concerned with the lives of children and adults with disabilities. It would be a tragedy if only one child was denied needed health care or only one family forced into bankruptcy trying to pay for uninsured health care. But we know all too well that there are thousands of such tragic stories. That is why this editorial, like William Sciarillo's fine article in this issue, urges readers to take an active role in the health care reform process.

We have spoken with a number of people with disabilities, parents and professionals who have been invited to share their views on health care reform with the President's task force.

All have come away greatly impressed by the breadth and depth of knowledge, willingness to listen and compassion shown by Mrs. Clinton, Mrs. Gore, the President, the Vice President and various task force staff.

By the time our thousands of readers receive this issue of *Exceptional Parent*, the details of the President's health care reform package will have been released. Health care reform will be the topic of much debate in Congress, in the media and among thoughtful, caring citizens across the country. "Special interest" groups will be hard at work lobbying for or against specific features of the plan while ordinary Americans try to figure out how the reforms might affect their day-to-day lives.

The reform process offers parents, people with disabilities and advocates an historic opportunity to be heard and to make a difference. We need to tell our stories to everyone who will listen. Our friends, neighbors, fellow voters and local and national elected officials need to hear about:

- the pain and hardship caused by existing programs that exclude children with disabilities from health insurance coverage or exclude entire families from group insurance programs because one family member has a disability;
- the anguish of being trapped in a job or geographic location because changing jobs means losing health insurance;
- the frustration of being forced to

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accept low cost, generic products (wheelchairs, communication devices, etc.) or services—and these often obtained only after hours and hours of paperwork and telephone calls—because health insurance providers refuse to pay for more appropriate, specialized products and services;

- the stress of living with fear of financial disaster knowing that needed health care is not covered by existing insurance plans.

Many Americans still do not understand the critical need for change in the current health care "non-system." Telling our stories can make a difference. When our stories are told, I believe that the majority of Americans will agree that major changes must be made.

Our fellow citizens must also be educated about the differences between short-term and long-term costs. Historically, this message has been difficult to communicate. Many Americans fail to realize that investing in a child's needs today can mean vast savings in the future. We must find ways to explain that many health problems experienced by people with disabilities could have been *prevented* by appropriate intervention. The pur-

chase of a specialized mobility aid or specialized care *today* can result in large monetary savings in the future. Pay now... or pay *more* later.

It is up to each of us to examine the President's specific proposals, and to decide where we stand on each component. *Exceptional Parent* will strive to present further details and informed commentary in the months to come. It is not our purpose now to take a position on any one aspect of health care reform. The point of this editorial is to encourage every parent and advocate to speak out *now*, to educate people about the need for change. Too many children and families have been abused for far too long.

Just a few short years ago, adults and children around the world worried about the very real possibility of nuclear war. Today, despite a number of terrible geopolitical disputes, our fears of global nuclear annihilation have largely dissipated. Why? Because real people had the boldness to speak out and the courage to choose a new course. And they brought about incredible changes.

Members of Congress *do* read their mail. What if all the readers of *Exceptional Parent* sent a letter to

their legislators specifically explaining how health care reform could change their lives and the lives of their children? Be assured, our elected officials would take notice and respond constructively. And suppose each of our readers were brave enough to call a talk show, write a letter to the editor of a local newspaper or speak out about health care reform in some other public forum. With real stories from real people, public support for major changes would intensify.

The President has presented his proposals. Some resist change because they fear the unknown. But we believe that most Americans, including most health care providers, know that our health care programs are not working effectively for many citizens and that the situation is worsening with each day. With or without our involvement in the process, changes are inevitable. By choosing to be involved, we can determine the form such changes will take. Let us resolve today that we will take every possible action to ensure that these changes respond to the needs of children with disabilities and their families. ■

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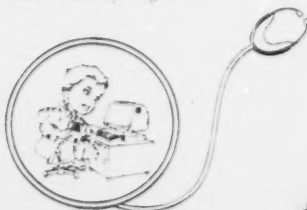
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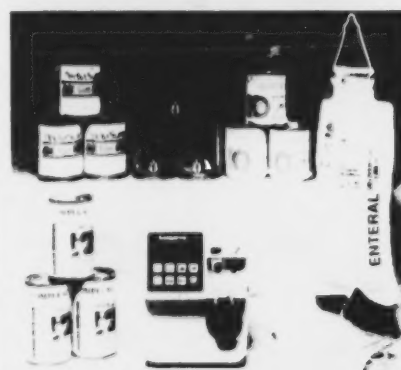
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have impaired hearing.*

Detecting a hearing loss

Many health-related factors can influence a child's inherent ability to hear properly. Children with disabilities such as Down syndrome, cerebral palsy or cleft palate often have impaired hearing. Head trauma and bacterial or viral diseases can also cause hearing loss. Even some drug therapies can affect hearing by killing hair cells in the inner ear.

Your child may have a hearing loss if he or she:

- hears voices when people are talking but has to strain to understand their words (You may find that this problem occurs frequently or that it happens only with certain people or in certain situations.)
- often asks people to repeat what they said
- frequently complains that people mumble
- plays the TV or radio very loudly
- cannot hear the doorbell or the telephone
- finds that looking at people when they talk makes what they say easier to understand.

Take your child for a hearing evaluation if he or she shows any of these symptoms on a regular basis.



Audiologists

An *audiologist* is a health care professional who specializes in preventing, identifying and assessing hearing impairment. At least 41 states require that audiologists be licensed to practice.

An audiologist can:

- give your child a thorough hearing evaluation
- recommend a hearing aid—and adjustments—to meet your child's specific needs. (Many audiologists also provide, fit and adjust hearing aids. Others refer clients to a hearing aid distributor.)
- teach your child how to use a hearing aid
- suggest other ways to improve hearing.

For a list of audiologists in your state, contact: American Speech-Language-Hearing Association (ASHA), 10801 Rockville Pike, Rockville, Maryland 20852, (800) 638-8255 (U.S. and Canada).

Hearing evaluation

An audiologist will use special equipment to measure your child's hearing of different "pitches" and understanding of spoken words. After testing both ears, the audiologist will explain the type and degree of any hearing loss.

If your child has a pattern of hearing loss that can usually be corrected by medication or surgery, the audiologist will refer you to a physician who specializes in diseases of the ear. Or, the audiologist may suggest that you contact your pediatrician. Federal law requires children to be examined by a licensed physician before they are considered for a hearing aid.

Not all hearing loss is permanent. Some tumors that impair hearing can be removed. And otitis media, an inflammation caused by fluid buildup in the area

behind the eardrum, causes hearing impairment that is usually temporary and can be treated by medication or surgery. Frequent bouts of this common childhood condition, however, may cause permanent damage to the eardrum, the bones of the ear or the nerve responsible for sending sound signals to the brain.

If your child's problem cannot be medically or surgically treated, more testing will be done to determine the most suitable type and model of hearing aid. If the hearing loss is bilateral, the audiologist can also determine whether your child needs to wear two hearing aids. Once the testing is finished, the audiologist will provide you with the recommended hearing aid(s) or help you to find a hearing aid distributor.

How hearing aids help

With a hearing aid, your child will hear some sounds that he or she has never heard before, or at least hasn't heard in a long time. The child will need to learn how to "tune out" background noises. Sometimes speech sounds will sound different than the way he or she thinks they should. It may take several weeks for the child to adjust to the hearing aid.

A hearing aid should help your child hear, but not necessarily in all situations. Despite technological advances and good follow-up care, hearing when background noise is loud may still be difficult. As one hearing aid user said, "I couldn't get along very well without my hearing aid, but it's no substitute for an ear."

Hearing aid components

All hearing aids have:

- a *microphone* to pick up sound
- an *amplifier* to make the sound louder
- a *receiver*—a miniature loudspeaker that delivers the louder sound into the ear
- *batteries* to power the electronic parts.

Some hearing aids also have *earmolds* (earpieces) to control the flow of sound into the ear, enhance sound quality and help hold the hearing aid in place.

Hearing aids differ in design, amount of power, ease of controlling volume and availability of special features. The audiologist will prescribe the most appropriate type of hearing aid for your child.

Before you buy...

Purchase the hearing aid recommended by your child's audiologist, but make sure that:

- you know why the recommended aid was chosen
- you receive a trial period
- the hearing aid has all the features that your child needs
- you know what kind of warranty comes with the aid, where and how quickly repairs will be done, and how often batteries will need to be replaced

- your child will receive quality follow-up care long enough to help him or her to adjust to the hearing aid
- your child will receive a well-fitting earmold (if needed)
- you carefully read any sales contracts before signing them.

Basic styles of hearing aids

Canal aids are contained in a tiny case that fits into the ear canal. They are the smallest aids available.

All parts of *all-in-the-ear* aids sit in the outer ear. These aids are larger than canal aids.

Audiologists usually prescribe *behind-the-ear* aids for children because smaller aids are easily lost and provide poorer amplification. A clear tube connects an earmold to the behind-the-ear aid.

Eyeglass aids are similar to behind-the-ear aids. But the parts are encased in eyeglass frames.

Cost

Prices vary according to hearing aid style, electronic features and the local economy. The price of a child's hearing aid can range from several hundred dollars to over \$1,000.

Purchase price should not be the only consideration for parents buying hearing aids for their children. Reliable products need fewer repairs and cause less frustration. The cost of special batteries and the rate at which batteries need to be replaced also influence the overall cost. Because each person's hearing difficulty presents a unique problem, the expertise of your child's audiologist and the need for follow-up services are important considerations.

Some health care plans cover the costs of hearing tests, hearing aid evaluations and even hearing aids for children. Medicaid reimburses the cost of some hearing aids. Check with your health insurance

company or your benefits officer to find out exactly what your policy covers.

Try before you buy

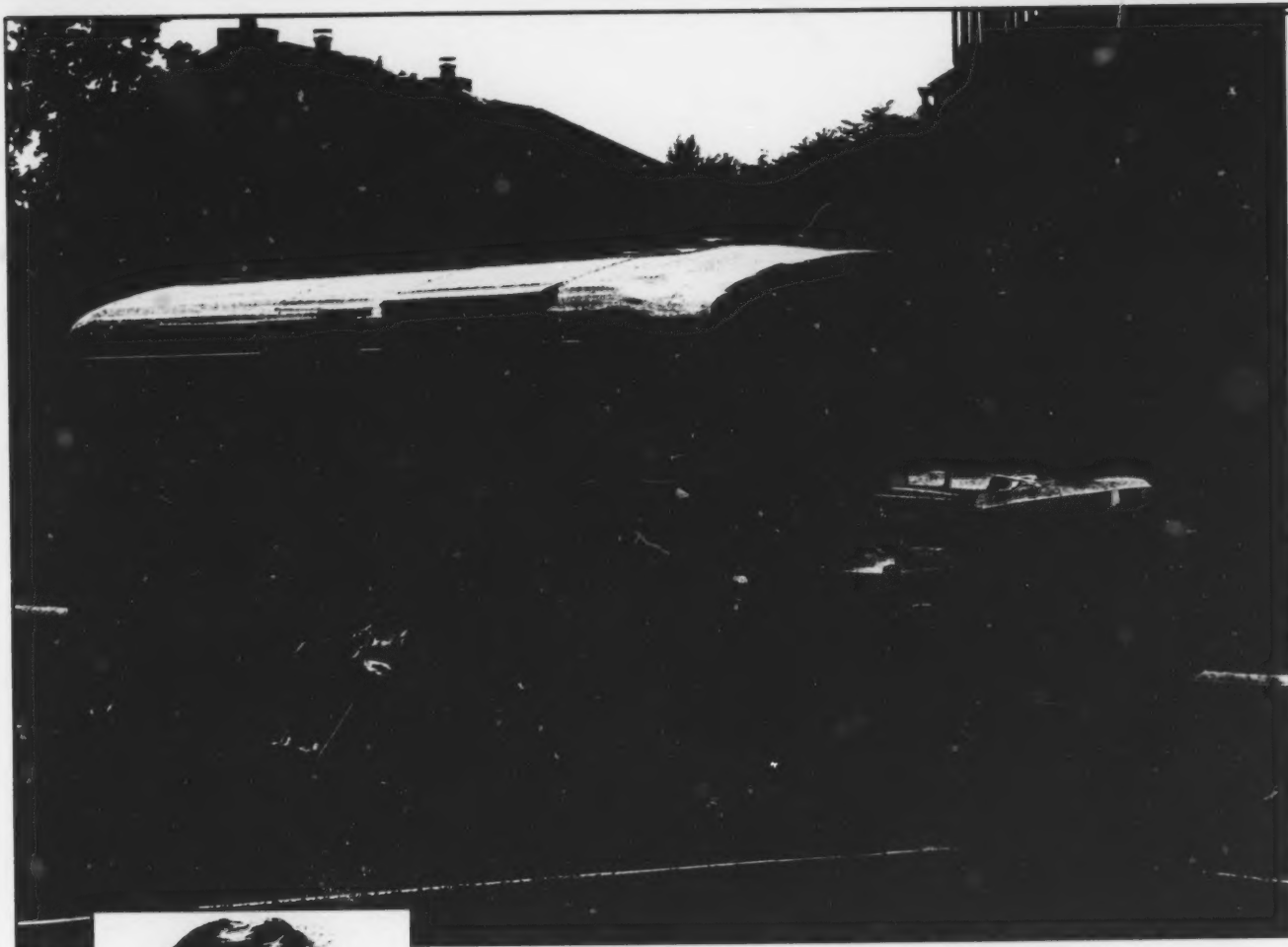
At least 11 states (CT, KY, ME, MN, NH, NY, OR, TN, TX, VT, WA) and the District of Columbia require trial periods for all hearing aid sales. Most audiologists will provide a trial period even if it is not required.

If you decide to cancel your purchase during the trial period, several fees may not be refundable. Non-refundable fees may include a fitting charge for parts, such as the customized earmold, and a fee for hearing aid evaluation. Discuss these policies with your audiologist. ■

Adapted from "How to Buy a Hearing Aid," published by the American Speech-Language-Hearing Association.

For a free copy write: American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, Maryland 20852.





Update on School Bus Safety

by Roseann Schwaderer

Bus companies, local school boards, parents and some transportation equipment manufacturers are trying to decide on the safest way for children who use wheelchairs to ride on regular school buses. Last January, the National Highway Traffic Safety Administration (NHTSA) published school bus wheelchair restraint regulations that safe seating advocates called discriminatory and inadequate (*Exceptional Parent*, March 1993). Supporters of comparable safe seating await decisions on two petitions that ask NHTSA to reconsider its regulations—and they have a lawsuit pending in the Sixth U.S. Circuit Court of Appeals that will move forward if NHTSA refuses.

Wheelchairs on regular school buses

At the same time, transportation officials, equipment manufacturers, attorneys and other concerned people have been discussing wheelchair restraint standards at forums such as the Second National Conference and Exhibition on Transporting Students with Disabilities, held in Georgia last March. Speaking at the conference, Michigan attorney Lynwood Beekman identified a range of possible ways to decrease liability risks brought about by transporting students in wheelchairs on school buses.

Beekman suggested that students could be transported in regular bus seats with seat belts and other appropriate restraints if they were lifted or assisted in and out of their wheelchairs. He noted that although it is illegal to carry students with disabilities on and off school buses, once on board students may be shifted from wheelchairs into regular bus seats. Beekman cautioned that his suggestion would not be feasible without a careful plan to secure wheelchairs in a safe place and to evacuate all students from the bus in an emergency.

Transportation seating review checklist

Beekman recommended that a letter be sent to all parents of students with disabilities who use wheelchairs while being transported to and from school. The letter would advise parents of safety concerns and would suggest that parents and officials meet to go over a "Transportation Seating Review Checklist." The checklist would identify the type of wheelchair to be transported, any realistic alternative ways to transport the student in a motor vehicle, wheelchair securement and passenger restraint devices, padding and any extra supportive equipment that must be transported.

The letter would also remind parents that most users' manuals published by wheelchair manufacturers recommend against riding in wheelchairs in moving vehicles. At least one major wheelchair company affixes stickers that read "This wheelchair has not been approved for use as a seating surface within a moving vehicle" directly onto its product.

Parent involvement

Parents must make it clear to manufacturers that they are concerned about motor vehicle transportation for their children who use wheelchairs. Only then will manufacturers design transportable mobility devices and set appropriate standards for wheelchair tie-downs and passenger restraints. Advocate and transportation official Lyle Stephens encourages parents to read literature on specific wheelchair models and to ask manufacturers which wheelchairs can serve as safe seats in motor vehicles. "Put the heat on manufacturers," he advises. "[Ask] Is this a transportable wheelchair?"

Developing transportable wheelchair standards

User preferences rather than inadequate technology may be why most wheelchairs cannot be safely transported in motor vehicles. It's a pretty good bet that all major players

in the mobility device business could build a wheelchair that would pass a standard crash test. But such a wheelchair would be too heavy to satisfy consumers.

Another dimension of the problem involves certification testing of tie-downs and restraints. Testing needs to be more systematic—restraints, tie-downs and chairs that will be used together should be tested together. The development of effective testing procedures and standards for restraint and tie-down strength and placement is a major topic of debate among transportation organizations such as the International Standards Organization, the Rehabilitation Engineering Society of North America and the National Standards Conference for School Bus Operations. These and other organizations are working together to develop standards for a transportable wheelchair prior to the May 1995 meeting of the National Standards Conference, so that state and federal governments may begin to write these standards into law.

Recent developments strengthen efforts

While progress may be slow, awareness of the need for safety is growing. Now, more than ever before, special educators, transporters, school nurses, occupational and physical therapists and parents can be found working together to ensure that a "free, appropriate public education" includes safe transportation to and from that educational setting.

These individual efforts have been strengthened by several recent developments on the national level. The newly-implemented Part H of the Individuals with Disabilities Education Act (IDEA) deals with education for infants and toddlers. This brings the issue of safe school bus seating for children of all sizes to the forefront.

Another relevant development is the formation of the Interagency Coordinating Council for Children with Disabilities, which held its first meeting in Washington, D.C., in August. The Interagency Coordinating Council is the first congressionally mandated interagency committee to formally include parents as members.

A third development is the enactment of the Americans with Disabilities Act (ADA), which raises the general level of awareness of access, mobility and safety issues. The ADA now requires that private school systems provide the same type of accessibility that IDEA and Section 504 of the Rehabilitation Act of 1973 have long required of public schools.

For the moment, concerned parents and transportation officials eagerly await the outcome of NHTSA's regulatory review or possible Appeals Court proceedings against them. Advocates for comparable safe seating hope these actions will result in a higher level of school bus safety for all children with disabilities. ■

Roseann Schwaderer is the founding editor of Transporting Students with Disabilities newsletter and publisher of TD Safety Report, a newsletter that focuses on the ADA and transportation. She is also executive director of the Sweetwood Foundation, a non-profit company that operates the Clearinghouse on School/Special Transportation. For information on the publications, please write: Roseann Schwaderer, c/o Serif Press, Inc., 1331 H Street NW, Washington, D.C. 20005.

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*James having fun
with one of his
many friends.
Jacob Sweet
often referred to
as "his main-
man."*

Images of Fathers

by James May

As the project director for the National Fathers' Network, I have spent the past seven years crisscrossing the country developing programs for fathers of children with special needs. I have visited thirty-two states and

completed more than 100 trainings. I have experienced the bitter cold of Maine, the tropical climate of Hawaii and the scorching heat of Texas. Through my travels, I have met many men who are working to be the best possible dads for their children with disabling conditions or chronic illnesses. Out of their common base of experience, these men have shared their moving stories and their efforts to be competent, concerned caregivers.

I remember two men who came to the first meeting of a Fathers Group and were surprised to find each other at such a gathering. With amazement and some embarrassment they discovered each had a child with a disability. The men

had worked together for the past four years but never shared this "secret."

I see and hear variations on this story almost everywhere I go. What stands out is the isolation so many men experience because they are afraid to share their special world, fearful of being misunderstood and often unwilling to reach out to others for help. So many still believe that a man is supposed to take charge, be self-sufficient and handle all his problems without asking for help. The old male stereotypes die hard. To finally be able to talk openly about one's child is an incredibly powerful experience. When we talk to each other we realize that we all have the same fears, angers, frustrations and joys. Isolation slips away.

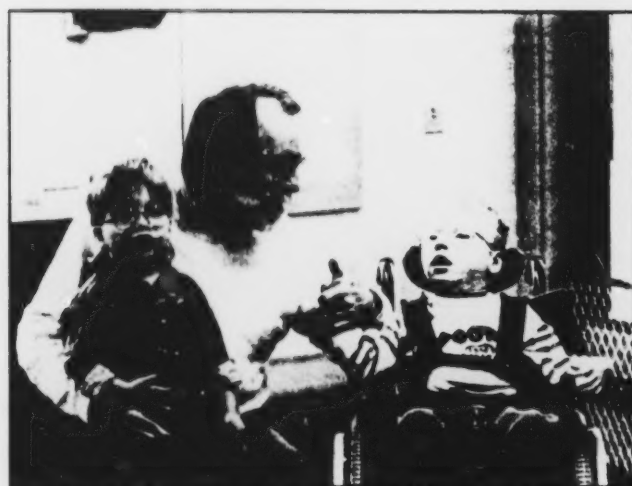
Some men simply deny their pain. A glib "I'm fine" or "everything's great" masks the confusion and concern men often feel about their families' struggles. I think of the silent, angry man who came to my home to install storm windows. After completing the job he asked to use a phone in my office. On my desk was a copy of a book about families raising chil-

With this issue of *Exceptional Parent*, we inaugurate a new regular feature, *Fathers' Voices*. This column will focus on fathers' experiences rearing children with special needs. What has the journey been like for you? What have you learned about yourself in the process? What has your child taught you and your family? We want to hear from you. Write to: James May, Project Director, National Fathers' Network, Merrywood School, 6120 N.E. Eighth Street, Bellevue, WA 98008.

dren with special needs. With a sudden blast of anger he asked me, "What the hell do you know about disabled kids?" When I told him about my work, he unleashed 20 minutes of unbridled rage. Fifteen months ago, his special needs child was born. Since that time he'd experienced anxiety about medical costs, stresses in his marriage and the loss of his job. This was the first time he had openly shared these thoughts with anyone else.

But behind the frustration and anger, it was clear that he felt immense love and concern for his child. I let him share his stories uninterrupted. When he finished, I told him about groups of men who meet to share similar feelings and support each other through their struggles. He was dumbfounded to learn that such groups existed. Like other fathers, he needed a safe place to release his frustrations, share his fears and joys, and reach out for understanding and acceptance.

I am continually struck by how a group of men from disparate backgrounds can find ways to connect with each other. A typical fathers' group may include mechanics and computer salesmen, loggers and professors, servicemen and engineers. I often begin a new session quietly wondering how these men will ever find something in common. I remember one man who remained absolutely silent throughout an entire two-hour session. He seemed utterly detached and completely bored. No amount of coaxing could elicit a response. Just as we were about to end the meeting, he finally looked up and began to speak about his child. He was hesitant at first but grew increasingly confident as he went on. He made it clear that the session had meant a lot to him and that he intended to return the next time. Obviously I had misjudged him.



James with his good buddies. Josh (left) and Jake (right). Children have always been the true love of his life. Perhaps that is because James has never quite grown up himself!

As I remarked later to the group leaders, we all have our own unique ways of sharing ourselves with others. While the men in the group seemed outwardly different, in reality they were very much alike. Underneath the tough exteriors was a tenderness waiting to come out and be acknowledged. Fatherhood of a child with special needs was the glue that bound them together.

I would be remiss if I failed to mention the laughter, good humor and delight the men bring to discussions about their children. They share a child's first steps, the mastering of a feeding session, the joy in taking a son swimming on a Saturday afternoon, the relief of making it through a child's heart surgery and the chance to take a daughter on a camping trip. These stories bring a special pleasure to our times together. Rarely do I leave a session feeling depressed or overwhelmed by sadness.

For dads of special needs children, success is defined differently. Fathers of children with disabilities rejoice in small victories, in progress however slow and measured, in hope after what had seemed so hopeless. For most fathers the child ultimately becomes a gift of love, a teacher. As one father proclaimed, "I feel proud of her [his daughter] and even proud of myself. I'm a damn good father. The irony is, I probably wouldn't have been if I didn't have a special needs child."

We hear much about absent or uninvolved fathers. The men I meet teach me to look past such stereotypes; instead, I see men working with great diligence to be compassionate, sensitive fathers. ■

For more information about the National Fathers' Network or to receive their quarterly newsletter, write or call: National Fathers' Network, Merrywood School, 16120 N.E. Eighth Street, Bellevue, WA 98008, (206) 747-4004 or (206) 282-1334. The National Fathers' Network is funded by a grant from the U.S. Maternal and Child Health Bureau, and is a subcontractor to the Association for the Care of Children's Health, Bethesda, Maryland. Portions of this article were previously published in Focus on Fathers newsletter, 1(7), University of Washington, Seattle, Washington 98195.

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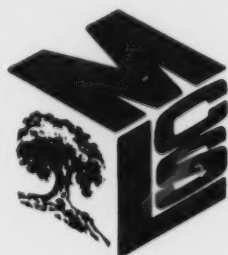
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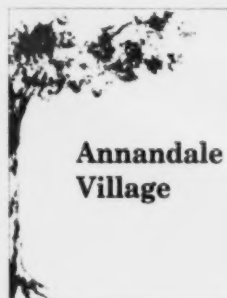
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Educational Excellence for All

by Lisa Blumberg

For children with disabilities to have positive experiences within the regular school system, we must insist both that our children be part of this school system, *and* that the regular school system be a place where *any* ordinary child can learn. We must remember that every issue affecting students in general also affects students with disabilities. A mother who wants a child with a disability to have access to a regular chemistry class may have to help her child fight the school's preconceived notions that the child is unsuited to learn chemistry. She may also have to advocate for necessary accommodations which will enable the child to participate fully in the lab work of the class. But before she begins lobbying for the school to meet her child's special needs, she may need to fight for something even more basic: she may have to join with other parents to oppose budget cuts which would eliminate chemistry from the school curriculum altogether.

Gains in access for students with disabilities will be nothing to celebrate unless we also succeed in improving education for *all* students. Other educational advocacy groups have done a poor job of reaching out to advocates for students with disabilities. We must show them that we have a common cause.

We also need to focus on defining the essential role of schools. All parents have the right to expect that schools will provide a safe and accepting environment where their children can acquire the academic skills needed to go on to higher education or gainful employment. A school's mission is no different when we are considering education for students with disabilities. All that must be added is educational accessibility.

Educational accessibility means removing architectural barriers and supplying large print textbooks to visually impaired students. It means providing a student with a learning disability with the one-on-one instruction he or she may need to learn math.

Children with similar disabilities should not be grouped together in a single class, but still need opportunities to get to know each other. This could be done in a variety of ways, depending on the age-level and interest of the students. A school might offer after-school recreational activities—such as adaptive sport programs—oriented towards kids with disabilities. Students with disabilities could be invited to work together on specific projects. For example, students who enjoy working with computers might want to produce a disability awareness booklet to give to classmates and teachers. Others might want to put on an assembly for the school on a theme which may not necessarily be disability-related. Programs where older students with disabilities act as mentors to younger students—helping them both with their school work and with their relationships—might be especially useful. High school students might appreciate being given a space where they can meet to discuss common concerns and work on the disability issues of their choice. These activities would help alleviate the isolation that some children with disabilities may feel without segregating them from the school as a whole. It is crucial that participation in all these activities be entirely voluntary, and that students without disabilities be welcome to join in.

I believe, however, that the successful inclusion of students with disabilities into school systems will be impeded if we insist that schools deal with all of a child's "problems." It may be unrealistic and ultimately counterproductive to ask that a school not only teach a child to read, but also teach him or her to walk.

We cannot afford to take the risk of under-educating our children. In

this computer age, the inability to use verbal symbols may be a bigger obstacle to employment than the inability to walk or even speak. If a particular child's education is fragmented to include therapeutic goals (which may or may not be achievable), the focus will be on the child's differences and attention may be diverted away from his or her actual education. Students and their parents often feel that a school is inappropriately, and quite possibly incompetently, involved in aspects of the student's life which they would prefer to handle outside of the educational setting where it will not detract from the child's learning.

Of course, the state has a duty to help children obtain any therapy needed to minimize a disability. It is also true that schools need to consult with different types of professionals in dealing with accessibility issues. The time has come, however, to consider whether occupational therapy, physical therapy and other *rehabilitative* services can be more appropriately and effectively provided in a setting where they will not interfere with education.

It is not easy to deal with these issues. We need to be open to new ideas and examine our own prejudices and preconceptions. We need to ask whether concepts which may have been considered progressive in the seventies are still relevant to the nineties. Above all, we must change the focus of the debate from mainstreaming versus special education to defining "excellent education" and assuring that this excellent education is accessible to *all* children. ■

Lisa Blumberg is a corporate lawyer for Aetna Life Insurance and lives in West Hartford, Connecticut. She has cerebral palsy and has attended regular schools and classes all her life. She graduated with a bachelor's degree from Wellesley College and a law degree from Harvard Law School. She is a member of the Exceptional Parent's Editorial Advisory Board and is a frequent contributor to the magazine.

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Holiday Toys

continued from page 22

the item requires any other purchase—like batteries or switches—to make it usable, or if it requires an electrical outlet.

With parental creativity, children with special needs can have toys and games that challenge their emerging abilities and enable them to interact with their environment. What is more

important, toys that truly "fit" give children with disabilities something that the rest of us may take for granted—a sense of control over their world. ■

Resource persons

Thanks to the following individuals for their assistance in preparing this article:

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The Gift of Love

Dear Santa Claus:

When I talked to you at the department store today, I did not have time to tell you all the things I wanted. In addition to a pony, a dog, a new television, a motor bike and a baby sister, I would also like...

Fortunately even Santa has some limits—the size of his sleigh, the pack on his back, his ability to negotiate himself and his pack down the chimney, or through the vents as the case may be.

This is the season for the exchange of gifts in most families. Parents must choose appropriate gifts for all of their children. Hopefully, everyone will enjoy giving as well as receiving. The most important gifts exchanged between parents and children at any time of the year, however, are care and love. Material gifts are but symbolic of the giver's feelings about the receiver. The number or price of material gifts certainly does not affect the quality of love.

Parent's love must also include helping the child understand his own limits. This is especially true for the parents of a child with a disability. Some parents find themselves looking for extra and special presents for the child in a fruitless attempt to make up for the child's deficits. Sometimes aloud and sometimes in silence, parents and the child share the wish for the gift of a miracle. No mortal can provide such a gift. Instead, the parents have a task that, when accomplished, seems like a miracle. Their task is to provide love for the child in ways that include enabling the child to accept himself and his limitations and yet maintain the courage and

hope necessary to lead as full a life as possible. In addition, parental love requires helping the child to accept the limitations of all human beings, including parents.

Other relatives may also want to "help the disability" with extras. They need to be reminded that the plea of the child is: "treat me like everyone else," and the plea of the child's siblings is: "I am a part of this family too—I understand the special needs but I have trouble understanding the special privileges."

Many parents face conflicts within themselves on gift-giving occasions. Parents may feel that they have not given a child enough this year (or in some other time in the past). They may have been preoccupied with financial problems, illnesses or community activities. Sometimes this feeling of not giving the child enough is related to the parents' feeling that they have been short-changed. They may believe that they can undo this feeling by showering the child with gifts.

At times, all parents feel they can never give enough to their children. At other times, they may feel depleted and think they have no more to give. If you find yourself feeling that you need to give more and make up for the past by showering your child with gifts, stop to consider exactly what you are doing. Think about your life, the life of your family and your own commitments and priorities. Your feeling that you have not done enough is probably an inappropriate and unfair judgment on yourself. On the other hand, it may be a realistic judgment that does require efforts for change. In either case, showering the child with gifts is a short-term non-solution. You cannot really "make up for it" all at once.

Parents who feel, realistically, that they have not given enough to their children (or to their spouses) owe it to themselves and their families to look to the new year as a time to reorder their priorities. A consistent daily effort to understand the needs of our loved ones and to give them realistic encouragement is a gift of love that transcends all seasons. While reassessing their priorities, parents should also give themselves some gifts. All too often, parents of children with disabilities find themselves sacrificing much of their lives in the interest of their children. It's fine to dedicate your life to caring for your children, but don't give up your own life in the process. Find ways to nourish yourself as well as your family.

Parents can also demonstrate their love by showing their appreciation for the gifts given to them by their children. Sometimes, children, especially children with disabilities, feel that they do not contribute to the joy and excitement of holidays. By involving children in the fun of selecting or making a gift for a parent, sibling or relative, they will learn that they can give as well as accept love. Since grandparents as well as children may sometimes feel left out, they too can be invited to join this joyful process of giving and receiving.

Sometimes, our gifts are not appreciated—no matter how considerate we have been. Such situations are aggravating but should not be used as a measure of one's competence. Instead, on such occasions, remind yourself that as a parent and human being, "you can't win 'em all," and wish yourself a happy holiday.

—S.D.K.

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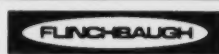
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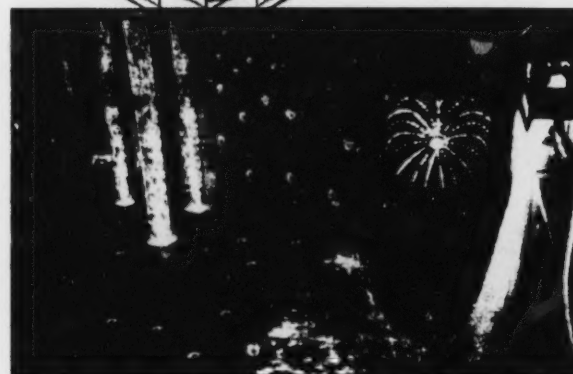
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According to The Arc, family supports are "whatever it takes" to prevent a person with a disability such as mental retardation from being placed outside their natural home. Family supports encompass a wide range of services, including home modifications, family training, respite care and even cash subsidies.

TDD users may order the informational pack by calling 1-800-855-1155 and asking the TDD operator to place a collect call to 817-277-0553. The information kit may also be requested by writing to: The Arc, P.O. Box 1047, Arlington, Texas 76004.

Study on Bus Access Released

The Office of Technology Assessment (OTA) has released a report that explores one of the most complicated elements of the ADA—access for individuals with disabilities to buses with a high passenger deck, otherwise known as over-the-road buses.

The report, *Access to Over-The-Road Buses for Persons with Disabilities*, was required by the ADA and provides information to assist the

Department of Transportation (DOT) as it develops regulations informing bus operators of their compliance obligations under the ADA.

Copies of the 160-page report may be ordered from: Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402-9325; phone (202)783-3238. The GPO stock number is 052-003-01320-7 and the price is \$9.00.

ADA Guide

The Americans with Disabilities Act: A Guide for People with Disabilities, Their Families, and Advocates is a 64-page reader-friendly book which describes how the ADA, passed in 1990, prohibits discrimination against the estimated 43 million Americans with disabilities. It explains the ADA definition of "an individual with a disability," clarifies who is covered and who is not, and provides information on the law to enable individuals with disabilities to attain greater independence and integration in society.

The Guide discusses and provides examples of how the ADA outlaws discrimination in:

- employment
- transportation
- services provided by state and local government
- services and accommodations offered by private businesses, and
- telecommunications access for people with communication impairments.

It also notes the effective dates of various ADA provisions, outlines rights and remedies for an individual cases of discrimination, and lists responsible agencies and other ADA resources.

Accessibility Guidelines Checklist

This checklist can be used to survey the design, construction, and alteration of public accommodations, commercial facilities, transit facilities and state and local government facilities in applying requirements of the ADA accessibility guidelines to buildings and facilities subject to the ADA. Intended for technical assistance purposes only, the checklist presents information in summary form on the Department of Transportation (DOT) and the Department of Justice (DOJ) access standards and the ADA accessibility guidelines. A single copy is free. Write to: Architectural and Transportation Barriers Compliance Board, Suite 1000, 1331 F Street, NW, Washington DC 20004-1111. Toll-free 1-800-USA-ABLE, (202) 272-5434 (Voice), (202) 272-5449 (TDD), (202) 272-5447 (FAX).

The Recreation Access Advisory Committee is expected to meet several times, all meetings will be held in the Washington, D.C. area and will be open to the public. For further information about the committee, contact the Access Board at (202) 272-5434.

The Guide was prepared at PACER for the Peer and Family Training Network Project on ADA, which is coordinated by the Parent Information Center (PIC) in Concord, New Hampshire. The project was funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR).

The cost of the ADA Guide is \$8.00, which includes postage and handling. Order from: PACER Center, 4826 Chicago Ave. S., Minneapolis, MN 55417-1098. For more information, call (612) 827-2966.

How Does Your Child Hear and Talk?

How Does Your Child Hear and Talk?, a brochure about speech, language, and hearing development, provides an easy-to-read chart on speech, language, and hearing milestones in children from birth to age five. A checklist spanning eight age ranges also helps parents to evaluate their child's communication abilities.

The brochure is available free of charge from the American Speech-Language-Hearing Association (ASHA).

To obtain a copy of *How Does Your Child Hear and Talk?*, call ASHA's Information Resource Center at 1-800-638-8255. ASHA's Information Resource Center provides free information on speech, language, and hearing problems and offers referrals to local certified audiologists and speech-language pathologists through the toll-free HELPLINE number listed above.

Miami VACC Camp '94

The 1994 session of Miami Children's Hospital's annual week-long VACC Camp for ventilation-assisted children and their families will be held in Miami Saturday-Friday, April 2-8, 1994. Application due date is January 15, 1994.

This free, community-based camp program provides recreation and social support for children with trachs, vents, C-PAP, or other ventilation devices; their parent and siblings at least 5 years old. Technology-dependent children should have normal cognitive potential.

For information contact: Director Moises Simpser, M.D. or Program Coordinator Cathy Klein, Ventilation Assisted Children's Center, Div. of Pulmonology, Miami Children's Hospital, 3200 S.W. 60th Court, Suite 203, Miami, FL 33155-4076 (Phone: 305-662-VACC).

Friends Who Care

The National Easter Seal Society has created an award-winning school program designed to help children understand what it means to have a disability.

Distributed to more than 30,000 schools over the past five years, *Friends Who Care* is a disability awareness curriculum suitable for classes of children in primary grades through junior high school.

Teachers use posters, a 16-page teaching guide, hands-on worksheet activities and a 45-minute videotape to encourage students to think about vision, hearing, learning, developmental and physical disabilities. These activities are designed to teach students about the variations within each disability. In the section about vision disabilities, for example, students look through wax paper to understand vision impairment and walk around

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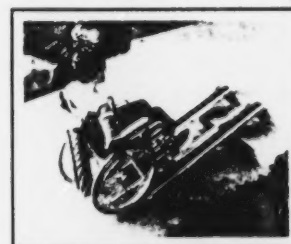


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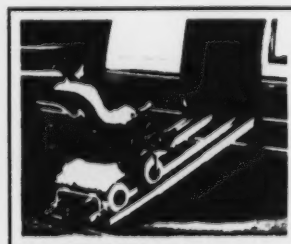


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with their hands on either side of their faces to better understand tunnel vision. Students also are asked to evaluate the school's accessibility as if they use a wheelchair.

Another key segment of the program suggests topics for discussions with guest speakers or disabled children who attend the schools. Introducing children to people with disabilities encourages them to ask questions and see how people with disabilities adapt.

Initially funded by a grant from Ronald McDonald Children's Charities, *Friends Who Care* is available for \$25, including postage and handling. Checks or money orders should be mailed to: *Friends Who Care*, National Easter Seal Society, 230 West Monroe, 18th Floor, Chicago, IL 60606. For more information, call (312) 726-6200, voice or (312) 726-4258, TDD.

Daily Folic Acid Use Reduces Birth Defects

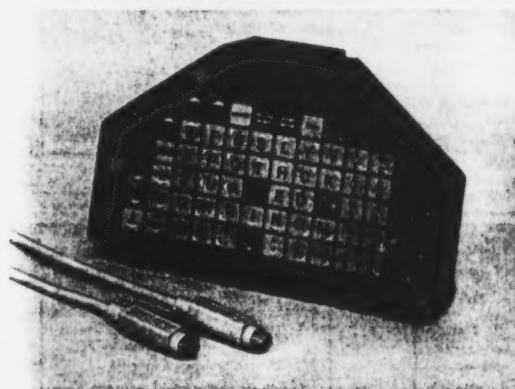
According to the American Academy of Pediatrics (AAP), all women capable of becoming pregnant should take folic acid daily to help prevent common birth defects such as spina bifida. The AAP also calls upon government to fortify food with folic acid—especially beneficial in cases of unplanned pregnancies.

In a policy statement, the AAP advises women who have no prior history of birth defects in their offspring to take a daily, over-the-counter multi-vitamin containing 0.4 mg of folic acid. Such action may prevent neural tube defects (NTDs) by as much as 50 percent. If a woman's previous pregnancy resulted in a fetus with an NTD, she should take a much larger dose—4.0 mg of folic acid—beginning one month before she

plans to become pregnant and continuing throughout her first trimester. NTDs occur in approximately one out of one thousand births in the U.S. Ninety-five percent of children with an NTD are born to couples with no family history of any of these defects.

According to the AAP, "...data [has] conclusively demonstrated that daily 4.0 mg doses of folic acid before and during early pregnancy resulted in a 71 percent reduction of recurrence of NTDs in this group of high risk pregnancies." The AAP cautions that women in this situation should not try to meet the 4.0 mg dose of folic acid by taking too many over-the-counter or prescription multi-vitamin with folic acid because they may ingest harmful levels of other vitamins.

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Kindness

by Jonathan Derr

We learn from the Torah that we should be kind. The kind farmer leaves some of his crop for poor people and strangers. The unkind farmer keeps all his crops for himself.

If I were a farmer, I would leave some food in my field. This way, the poor and the strangers could pick the food. They could bring the food to their families and children. I would want this to happen because I don't want them to starve.

There are other ways to be kind. We can help children. We can build houses for poor people to live in. We can be kind to people we know and love.

In my life, lots of people have been kind to me. And now I want to thank them and tell them that I love them.

Dad, thank you! You taught me to love sports. When I was a kid you showed me how to play basketball and baseball. More importantly, you taught me never to quit. You taught me that I am a hero whether I win the game or lose.

Mom, thank you! You are so special to me! You taught me how to be a great person and a great kid. When I was in the hospital I knew you would always be there for me and on my side. Thank you for the special love and care which I feel in my heart.

Nana, you are a wonderful grandmother. I remember the stories you read to me when I was little. You also showed me special love and care.

Emily, I love and care about you. You are a great sister. I love the hugs and kisses you give me. And I promise to be a better brother to you.

And I especially want to say thank you to Pa. You, Pa, showed me special love since I was a baby. I remember how you carried me on the beach. How you gave me hugs and kisses, bought me ice cream, taught me to swim, and play golf. When I get older, I hope you will always be my golf mate.

And thanks to Grandpa and

Grandma Derr. Your son is a great father.

Finally, thanks to all my family and friends, including those of you who came from so far away. I also want to remember my cousin, Doug, who is not here with us.

And thank you, all my teachers and friends, who have been so kind to me. You mean very much to me on this important day!!



Dad's Speech

by Chet Derr

Jon, today on your Bar Mitzvah your mother and I are especially proud of you. You have worked very hard to make this day a success. You have shown us that with hard work and determination anything is possible.

You said in your speech that I taught you never to give up and to always do your best. Well, you have taught us a lot, too. You showed us that what some people would call a rough start can be turned into a huge success story if people are willing to give you a chance.

I want to take this opportunity to

thank your mother on your behalf. She is the one, Jon, that fought so hard to get you those chances. Without her on your side we probably wouldn't be here today. You never would have had a chance to steal home and nobody at Camp Bauercrest would know Jon Derr.

Jon, you told me a few months ago that there are four phases of life. The first phase was when you were a baby. The second phase is when you are a boy. The third phase is when you are a man. And the fourth phase is when you are old like Pa, you said. Jon, today is your first day of phase three, congratulations.

Mom's speech

by Jo Ann Simons Derr

Jonathan, I am very proud of you today.

I am filled with love and respect for you. You have worked very hard for your Bar Mitzvah and you were terrific.

Jonathan, you have had a lot of teachers, and a lot of people who cared for you and about you. A lot of them are here with you today. But, Jonathan, you have also been our teacher.

Since you were born, you have taught us. You have taught us about courage, acceptance, patience, honesty and friendship. You have also taught us about love. In your beautiful Bar Mitzvah speech you spoke of the special love you have received but, you have also given special love. I feel your special love every day.

You have given us many opportunities to be proud of you. You've hit line drives into left field, you stole home on a wild pitch, you've comforted me when I've been sad, you've won golden medals and championships, you've been gracious in defeat, you confronted our people's past when we visited Dacau. But, most of all Jonathan, you have tried your best every day of your life. Jonathan, you are a special young man and a good friend to many and the best son for this mother. I love you.

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Federal Health Information Centers and Clearinghouses

The Federal Government operates many clearing-houses and information centers that focus on specific topics. Their services include distributing publications, providing referrals and answering inquiries; this list includes those directly related to the care and education of children with disabilities. Many offer toll-free numbers. *This information is in the public domain. Duplication is encouraged.*

**Centers for Disease Control National
AIDS Clearinghouse** P.O. Box 6003
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(800) 342-AIDS (English hotline)
(800) 344-SIDA (Spanish hotline)
(800) 243-7012 (TT)
(301) 738-6616 (FAX)

**National Institute of Allergy and
Infectious Diseases**
Office of Communications
Building 31, Room 7A32
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-5717
(301) 402-0120 (FAX)

**National Arthritis and
Musculoskeletal and Skin Diseases
Information Clearinghouse**
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and Physically Handicapped**
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(202) 707-0712 (FAX)

Cancer Information Service NIH
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**National Clearinghouse on Family
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other Communication Disorders
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(800) 241-1055 (TT)
(301) 565-4020
(301) 565-5112 (FAX)

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(301) 770-5164 (FAX)

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(301) 770-5164 (FAX)

**National Information Center for
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(703) 893-6061
(703) 893-8614 (TT)
(703) 893-1741 (FAX)

Clearinghouse on Disability Information
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Rehabilitative Services
Department of Education
330 C Street SW
Switzer Building, Room 3132
Washington, D.C. 20202-2524
(202) 205-8241
(202) 205-9252 (FAX)

ERIC Clearinghouse on Teacher Education
One Dupont Circle NW, Suite 610
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(202) 293-2450

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Institute**
Education Programs Information Center
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(301) 951-3260
(301) 951-3269 (FAX)

**National Injury Information
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(301) 504-0124 (FAX)

**National Kidney and Urologic
Diseases Information Clearinghouse**
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Bethesda, Md 20892
(301) 468-6345
(301) 770-5164 (FAX)

**National Center for Education in
Maternal and Child Health**
200 North 15th Street, Suite 701
Arlington, VA 22201-7802
(703) 524-7802
(703) 524-9335 (FAX)

**National Maternal and Child Health
Clearinghouse**
8201 Greensboro Drive, Suite 600
McLean, VA 22102
(703) 821-8955, ext. 254 or 265
(703) 821-2098 (FAX)

National Institute of Mental Health
5600 Fishers Lane, Room 15C05
Rockville, MD 20857
(301) 443-4513

Office of Minority Health Resource Center
P.O. Box 37337
Washington, D.C. 20013-7337
(800) 444-6472
(301) 565-5112 (FAX)

**National Information Center for
Orphan Drugs and Rare Diseases**
P.O. Box 1133
Washington, D.C. 20013-1133
(301) 565-4020
(800) 456-3505
(301) 565-5112 (FAX)

National Rehabilitation Information Clearinghouse
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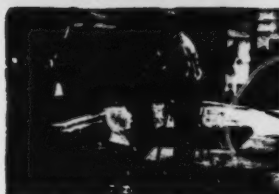
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¹ Ford Motor Company will authorize the selling Ford or Lincoln-Mercury dealer to pay the vehicle purchaser an amount equal to the cost of vehicle adaptive equipment conversion, up to a maximum of \$750.

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11th Annual Technology Issue

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General Motors
67

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PARENTING
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WITH A
DISABILITY

NOVEMBER/DECEMBER 1993

Volume 23 Issue 9

FEATURES

18 Health Care Reform—What does it actually say about disabilities?

Excerpts from the President's Health care reform proposal, and commentary from several perspectives.

24 New Technology for Artificial Arms

New technology allows a child with an artificial arm to use upper arm muscles to control a prosthetic hand.

27 Getting Started with Computers

What you need to now to begin exploring the exciting world of assistive technology.

33 Alliance for Technology Access Directory

State-by state listing of assistive technology centers.

36 Technology Use at Home

A survey of parents reveals current trends and continuing needs.

39 Reflections on a Birthday

Heidi's birthday provides her mother with glimpse of the future.

DEPARTMENTS

- 2 Editor's Desk
- 4 Letters
- 9 Family Support
- 40 Fathers' Voices
- 42 Research
- 43 Informational Forum: Networking
- 47 What's Happening
- 54 Media
- 62 Children's Page



Page 18



Page 27



Page 36

COVER: "This young girl has lost her new, myoelectric arm at the Vandy Myoelectric Center, Rehabilitation Institute of Michigan in Detroit."

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EDITOR'S DESK



Stanley D. Klein Ph.D.

Eleventh Annual Technology Issue

I encountered my first computer in 1964 at a seminar for health care researchers. The computer was housed in a three-story building. That a computer could be a useful research tool seemed obvious; but it was too hard for me to imagine that this large, unwieldy machine could be used for anything more. Not until 1972, when I was invited to the press presentation of the first Kurzweil Reading Machine, a machine that read printed material for people with visual impairments, did I begin to appreciate the potential impact of technology in the lives of people with disabilities. Even so, I certainly could not have predicted that we would, in our Eleventh Annual Technology issue, report on how current technology allows a child with an artificial arm to use nerve signals from muscles in her natural upper arm to move her prosthetic fingers (*New Technology for Artificial Arms*, p. 24) or about children with disabilities using telecommunications technology to send electronic mail to overseas pen pals (*Children's Page*, p. 62).

For many of us, computer technology remains rather frightening. We want to help our children take advantage of technology but we don't know where to start. After all, when we were kids, nobody had—or even expected to have—a computer. We may wonder how technology can help our child at school and at home. These issues are addressed by Madalaine Pugliese and Bill Davey (*Getting Started With Computers*, p. 27) and by Adele Schwartz (*Technology Use at Home*, p. 36). And if you're looking for a place to get some hands-on experience with what technology can offer your child, check out our *Alliance for Technology Access Directory* on pages 33-35.

Health Care Reform

Health care reform is a major priority for children and adults with disabilities, as well as for many other citizens. Thanks to the initiative of our President and Vice President and their talented and knowledgeable partners, major reforms are now under discussion. In this issue, we present excerpts from the first Administration report on the President's plan, along with editorial commentary and reactions from the Consortium for Citizens with Disabilities and Senator Robert Dole. In our February issue, we will again focus on this important legislation and bring our readers a range of perspectives from key leaders.

New Departments

Beginning with this issue, a "Research Page" will report on important research that is relevant to the lives of children with disabilities and their families. Beginning in 1994, another new department, "Role Models," will share stories about successful individuals with disabilities and parents.

1994: Twelve issues!

As we announced in our October issue, *Exceptional Parent* will become a monthly magazine in 1994. Our tentative Editorial Calendar is as follows: January—*Annual Directory of National Associations, Organizations, Products and Services*; February—*Early Intervention*; March—*Annual Mobility issue*; April—*Summer Fun*; May—*Recreation*; June—*Telecommunications*; July—*Teens*; August—*Health*; September—*Education*; October—*Holidays*; November—*Technology*; December—*Religious Education*.

We welcome editorial contributions from our readers. More information on upcoming editorial themes and our writers' guidelines are available upon request from our editorial offices (209 Harvard Street, Suite 309, Brookline, MA 02146-5005).

Book Services

We are in the process of expanding our book services. The address and phone number for placing orders has changed. Please see page 60 for up-to-date information.

Reader Survey

Many of our readers will be receiving surveys from us. The results of this survey will help us make *Exceptional Parent* even better. If you receive one of these surveys in the mail, please, take the time to complete and return it. Thanks!

—S.D.K.

EXCEPTIONAL PARENT

Parenting Your Child With A Disability

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Letters to the Editor

Parent Search Pays Off!

I want to thank you for printing my letter in the "Parent Search" section in the June 1993 issue of *Exceptional Parent*. My letter was entitled "Emotions Involved in Residential Placement." I have already begun to receive responses, and I feel very good knowing that there are other parents with children in residential placements who are dealing with the same pain and loss.

My son has been in placement for the past two and a half years. Until now, I had felt very much alone with my feelings and emotions, but reading these letters has helped me to feel less isolated. The letters have given me the strength to try to form a local support group for parents who have children in residential placement.

Thank you, *Exceptional Parent*, for being a truly exceptional and invaluable magazine for parents with children with disabilities.

V.S.
New York

Inclusion: Two Views

Thank you for such a wonderful magazine. My adorable ten-year-old son has cerebral palsy. I have been subscribing since he was an infant.

I enjoyed the articles on inclusion (September 1993). My son is being "included" in a third-grade class in our town. It was a dream we thought would never occur. Brian is a changed person since inclusion. He loves school and his classmates. Inclusion is working very well for us. It is well worth the hard work of all concerned.

H.M.
Massachusetts

■ As an educator and parent of a son with severe disabilities, I am so grateful for the special education classes and special schools my son has attended over the past 15 years. With his many problems, he has had wonderful opportunities that he would never have experienced in a "regular" classroom.

I believe that inclusion will result in a loss for children with disabilities,

their teachers and their parents. The "mainstreaming" of the mentally ill has resulted in homelessness and other serious problems for these members of society. I hope that inclusion does not mean an economic gain for school systems at the cost of long-range losses for children with disabilities and their parents.

J.G.
Ohio

Attention Deficit Disorder

I was pleased to see the article "Treatments for Attention Deficit Hyperactivity Disorder" (September 1993). Although this condition may not carry the visible stigma of more obvious disabilities, the psychological frustrations—experienced by both parent and child—certainly qualify it as a chronic medical condition. As a mother of a 10-year-old with this disorder, I can verify that this problem affects every aspect of his daily life. The frustrations that our entire family faces can sometimes seem overwhelming.

Fortunately, our son is under the care of a physician who is quite experienced with this disorder. In addition, he is involved in a social skills peer group, receives language therapy, individual tutoring and is in class to learn typing as an alternative to his poor handwriting (secondary to poor fine motor control). His new medication has been of great benefit in lengthening his attention span, and we are lucky to have a teacher this academic year who is willing to work closely with him.

Please continue to print articles on children with these "hidden disabilities." It gives parents a continual glimmer of hope and support.

S.L.
Kentucky

Labels

I was pleased to read the article "Labels Can Be Harmful" (July/August 1993) because it focused on mental health issues and the unique and individual difficulties faced by the family of a child or adolescent with challenging behavior, a serious emotional dis-

order or mental illness. We need more such articles to help eliminate the stigma attached to these issues—what I call the "shame and blame syndrome." These articles also inform families that they are not alone.

There is much emphasis in "labels" in neurobiological disorders. This excludes many children, including my own son. These disabilities do not always have their origins in genetics, nor can anything specific be found in MRI's, CT scans, EEG's, laboratory tests or parenting styles. These labels also exclude children who do not meet the traditional criteria for depression, bi-polar disorder, psychosis, etc. that were developed for the adult population. A label—or the lack of a label—should not shut the door to much needed services or create additional stress for families. Most states and the Federal government require the label "serious emotional disturbance" in order to access services. But who says it has to stay that way?

If all the families who have children and adolescents with mental health needs stand together and educate the public about this disability, lobby for equality in health insurance coverage and sensitize people to negative language, the world will be a better place for us and the children we love.

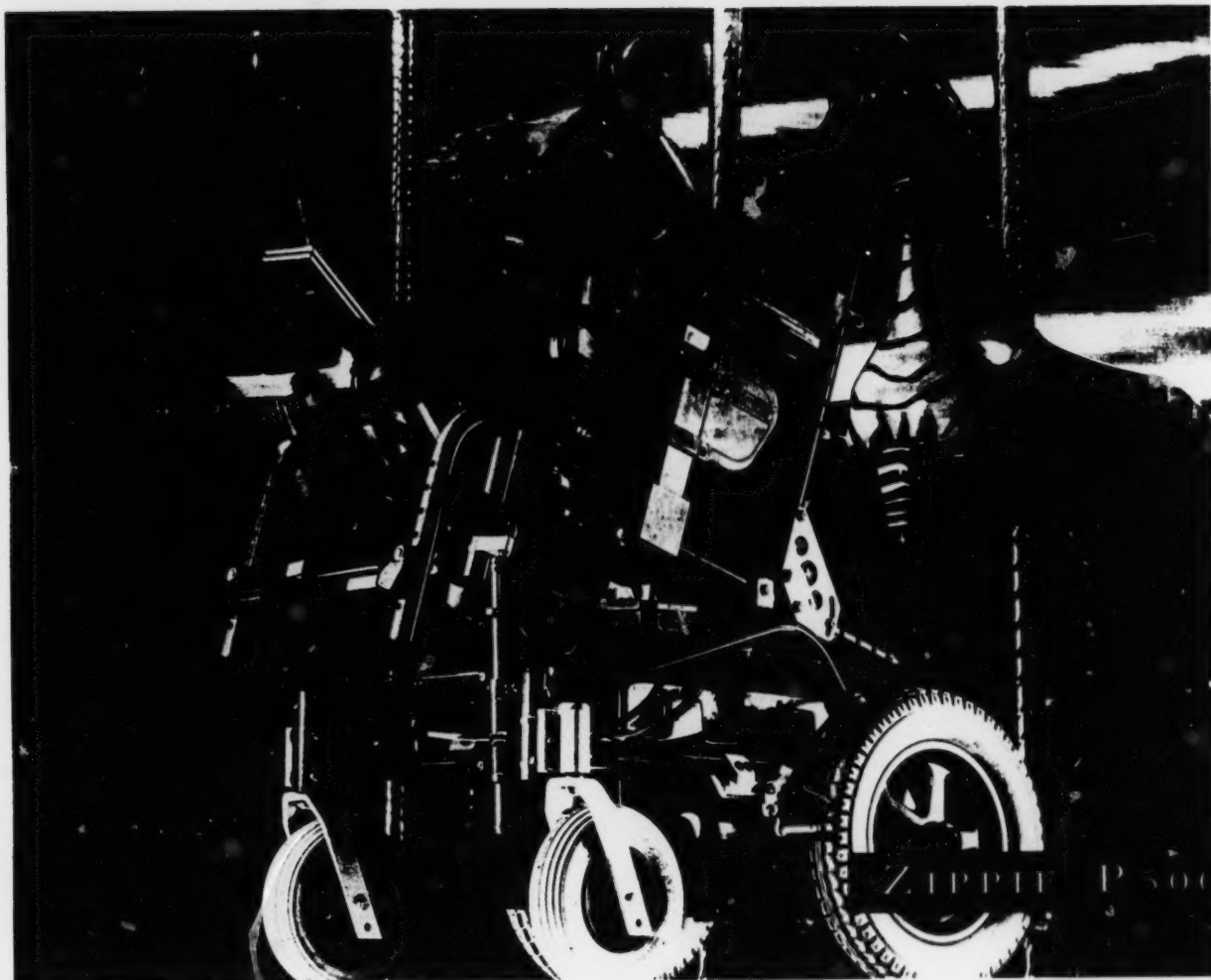
I also liked the "Family Support" theme of the July/August issue. Belonging to the Parent Support Network of Rhode Island, a parent-run organization for families that have children and adolescents with mental health issues, has been a life saver for me.

N.A.
Rhode Island

We welcome all letters from readers—reactions to articles, suggestions, opinions, complaints. Write or fax:

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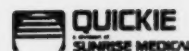
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More Labels

I cannot disagree with P.F.'s strict definition of mental retardation and learning disabilities (Letters to the Editor, July/August 1993—"Film's Description Wrong"). However, I find myself taking great offense at her letter's tone.

It is difficult to evaluate this letter's statement that children with learning disabilities "need special help to achieve their potential," but children with mental retardation "need other kinds of help." Many children with Down Syndrome are currently enrolled in classes "for the learning disabled." They are in these classes because they are actually functioning above the level to be expected by an IQ test. Either IQ tests are not that accurate (horrors!) or something else is going on here. The same techniques used to educate children with learning disabilities are sometimes effectively used to educate children with mental retardation.

I ask P.F.: Is it not theoretically possible that the child in the film has both Down Syndrome *and* a learning disability? Is it not theoretically possible that we don't understand mental retardation at all, or that IQ scores do not always predict learning abilities?

Your statement that associating your child with a learning disability with my child with mental retardation somehow "damages" your child is awful. When is my daughter good enough to be called LD instead of MR? Will you let her in your child's class if they brand her with a big red "retard" on her forehead—just so everyone knows the difference?

Parents of children with Down Syndrome have also "...worked so hard to have our children's innate intelligence recognized while at the same time building a network of support to enable them to achieve all they can despite some differences." Thank you for showing me that we still have a long way to go.

M.W.
Virginia

■ I find it hard to understand why P.F. would make statements about a film that she had admittedly not viewed. Why would anyone make statements about any subject without having the facts?

My impression of the film was that it was about the struggles and

joys of a child with a disability—not specifically about the disorder of Down Syndrome. The film gave a very candid view of the special education system and provided insights on mainstreaming.

P.F. stated that "to equate learning disabilities with mental retardation is to do damage to a generation of hard-fought and hard-won initiatives of the Learning Disabilities Association." I must confess that I do not know anything about the battles or victories of the Learning Disabilities Association, but I do know something about Down Syndrome. My daughter, Sarah, was born with Down Syndrome. I found the P.F.'s attitude and remarks to be very insensitive and based on ignorance. We parents of children with mental retardation have fought many battles also, but the attitude displayed in the letter is evidence that we have won very few—if any—victories. We also want people to recognize our children's intelligence. A child with mental retardation still has intelligence!

I was also very disappointed with the editor's note that simply said, "thanks for the correction." I had hoped for more understanding and better information from *Exceptional Parent*. Now I must ask you to correct your error and let your readers know that although the theoretical definition of learning disabilities and mental retardation may not be the same, all children with disabilities deserve understanding and respect from society.

Finally, I would like to say that my daughter's mental intelligence is the least of my concerns. It is very common for children born with Down Syndrome to have various medical conditions. My days are filled with inhalation therapy, suction machines, countless medications, doctor's visits, hospital stays, surgeries and many types of therapy. So if I seem more than appalled by the ignorance and insensitivity of such petty classifications demonstrated in this letter, I am sure you will understand.

P.B.
Georgia

From One Home to Another

I am responding at this late date to your excellent editorial "Liberty and Choices for All" (June 1993), written in regard to the article "Profound

Truths" by Kathleen M. Fagley (February 1993). I think your editorial very sensitively responded to those parents who criticized Mrs. Fagley for "placing" her child. I never liked the word "place"—Mrs. Fagley's child just moved from one home to another.

This issue has been with us for many years. As I read your editorial, I clearly recalled responding to a similar situation in 1981 when Carol Gott Gross wrote the article "We Chose to Place our Baby." A reader also responded to that article with scathing criticism.

Although I am an ardent advocate of the principle of inclusion for children with disabilities, I also support the parents' right to do that which is best for them and for their child. Society

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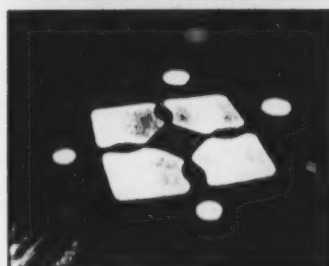


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casts enough guilt upon parents of children with disabilities that we parents have to make sure that we don't contribute to it by our comments.

I am sure that both sets of parents found answers that are right for them, and this reminds me of an old Jewish fable of a married couple who continually quarreled. They called in a neighbor to help settle their argument but when that failed, they all went to the local rabbi. He listened to the husband's story, and responded, "You are right." Then he listened to the wife's story and responded, "You are right." At that, the perplexed neighbor asked, "But Rabbi, you said he was right, then you said she was right—how can this be?" The rabbi responded, "You're right too!"

So let us remember this as one more coping mechanism.

B.P.
New York

■ Thank you for showing that you understand that residential placement of a child with special needs does not amount to a lack of love, concern, or support on the part of the child's family.

Choices are what parents have fought for over the years! That's what IEP's are all about. Children with disabilities are individuals first.

Family needs are also unique. It is unfair for other parents or professionals to presume to know that is best for my child or our family, especially those who have never even met us!

Please continue to represent the needs and choices of all families and individuals with special needs. Our choices are often difficult and we don't need criticism from those who don't know us or our children.

Keep up the good work!

B.A.
Illinois

Correction: In September's directory of "National Organizations for Specific Disabilities and Conditions," the phone number listed for the **Spina Bifida Association of Canada** was not correct. The number listed is for fax, not voice. The correct telephone numbers are 204-957-1784 and 1-800-565-9488 (Canada only).

Parents Search

Pseudobulbar Palsy

Our 12-month-old son, who was born three months premature, has been diagnosed as having pseudobulbar palsy, also known as suprabulbar paresis. The four significant characteristics are inability to swallow, brisk jaw jerk, micrognathia and upper body hypotonia. There appear to be no other involvement of the extremities. His MRI and CAT scans have all been normal. He is currently NG tube fed and requires 24-hour nursing care for airway maintenance, monitoring, and respiratory therapy. He is an alert and active child.

From the literature, we have been able to learn that some children with this condition eventually recover over a period of months or even years. We would like to locate other parents or physicians who may have experience with a child who has a similar condition.

V.W. & S.W.
Texas

Semilobar Holoprosencephaly

My ten-month-old daughter, Chloë, was diagnosed shortly after birth with a rare neurologic condition called Semilobar Holoprosencephaly. She also had multiple cardiac defects including a coarctation of the aorta (now repaired) and a huge ventricular septal defect which we are hoping will be repairable soon.

At the time of diagnosis, Chloë was given a very bleak prognosis. We were told her development would be severely delayed and she would probably never sit up, walk, communicate or understand language. At ten months Chloë is almost sitting on her own and can wave bye-bye. Now, doctors say that she will probably walk and be able to communicate. Because of its rarity, we have been unable to find information regarding the potential abilities of a child with her condition. I'd like to find other parents who have children with Chloë's diagnosis so we may get some insight.

M.M.R.
New York

Asperger Syndrome/Landau-Kleffner Syndrome

My five-year-old son was recently diagnosed as having Asperger Syndrome (some consider this condition to be high functioning autistic and others feel it is something totally different, but on the autism spectrum).

None of the doctors in my small, rural community has ever heard of Asperger Syndrome. My son recently had an EEG done and it came back abnormal, so now the words Landau-Kleffner syndrome (sometimes referred to as "acquired epileptic aphasia") have also entered the conversation. They consider my son's disorder to be very rare and have been unable to help him.

I am desperate to get my hands on any information regarding Asperger Syndrome or Landau-Kleffner syndrome. My husband and I are interested in research, treatment, prognosis, general information, related articles, support groups and corresponding with other parents who have a similar child.

L.N.
Oregon

Mitochondrial Myopathy

We have a six-year-old daughter who is diagnosed with a mitochondrial myopathy called chronic progressive external ophthalmoplegia plus syndrome with corneal involvement. Some refer to it as a variant form of Kearns-Sayre syndrome. Her symptoms include droopy eyelids, ophthalmoplegia, corneal cloudiness and corneal edema, muscle weakness and short stature. Due to the corneal involvement, she is severely photophobic. The corneal edema adds to her discomfort.

We would be very interested in hearing from anyone with a child who is similarly diagnosed.

L.C. & R.C.
Florida

Leber's Congenital Amaurosis

We are the parents of a five-year-old daughter, Courtney. She has Leber's congenital amaurosis. She was diagnosed at two months as being totally blind; now her vision is 20/100.

Courtney has mild mental retardation and neurological problems. She has speech problems, wears ankle splints, and does not walk on her own. She also wears diapers and drools a lot. We have been trying to work on both the diapers and the drooling, but have had little success. Courtney seems to understand almost everything that is said to her, but because of her speech it's hard to know for sure.

We know of five other children with Leber's, but none of them have problems other than vision. We would like to hear from other parents with a child or children like Courtney. Thank you.

R.S. & V.S.
Pennsylvania

Parents with Disabilities

Raising any child can be a trying experience at times. Raising a child with a disability is even more diffi-

Family Support, including Parents Search and Respond is an opportunity for our readers to exchange information about their practical experience meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether letter is a search or response. If a response, please be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters: some are published in **Parents Respond**.

Write or Fax:

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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD) 100 Rt 37, P.O. Box 8923, New Fairfield, Conn. 06812, (800) 999-NORD, (203) 746-6518. Also, see **Exceptional Parent's Annual Directory of National Organizations, 1993-1994**, published in the September 1993 issue.

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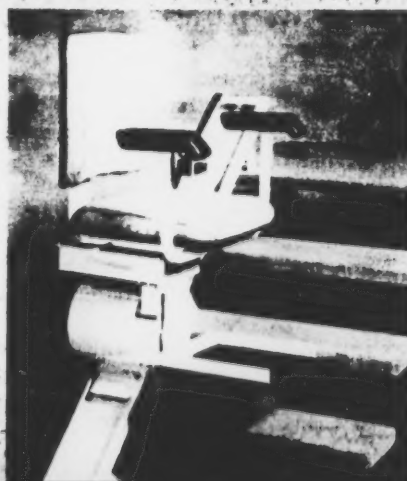


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cult—but my case involves a special problem.

I am the mother of a son, Brian, who is four years old. He was diagnosed with autism at the age of one. He attends a preschool for children with disabilities and is progressing slowly but steadily. I also have a daughter, Kara, who is a bright and energetic two-year-old. My husband passed away early this spring and while I miss him very much, I am also beginning to realize how important he was in the raising of my two children.

I have a neuro-muscular disease that at times gives me a lot of pain. I realize that I can raise my children and give them the kind of life that they deserve but there are times that I would like to say "No!" to all that is happening.

I wonder if there are any other parents with physical disabilities trying to raise a family. How do these parents cope with everyday problems?

*C.L.B.
Indiana*

Cerebral Palsy

My son Christopher is three years old and has cerebral palsy. From day one he has been a screamer and a crier. He can't talk, although he is very vocal with his sounds. He can't sit up without losing his balance. Christopher can't crawl or walk yet, either.

Now he is starting to grasp and play certain games. When he is happy he laughs like crazy, and these are the times that I live for. Christopher is aware of everything, and he understands things that are said to him. We are hoping to find other parents with kids that are going or have gone through this stage, and to learn how they coped or are coping. Maybe we can trade helpful hints!

*K.C. & J.C.
Kansas*

Undiagnosed

Our 11-month-old son, Dakota, is significantly developmentally delayed. He cannot sit without support, does not crawl, and is not making repetitive consonant-vowel sounds. He can, however, roll from stomach to back and and creep in circles on his stomach. He eats well, and is alert, happy and social.

Dakota has dysmorphic features which include slightly protruding eyes that are wide spaced, low set ears, nose with flattened bridge, high

palate, simian-creased left palm and low muscle tone. His heart has an a trial ventricular valve dysplasia with a possible mild AV-valve stenosis. His fine motor skills are at a 4-5 month level, and his gross motor skills are at a six- to seven-month level.

He has had many tests—high resolution chromosomes with Fragile X, EEG, MRI, skull x-rays, serum and urine amino acids, and organic acids. All have come back normal. Recently, he had a DNA test establishing that he does not have Kellian's Syndrome. My husband and I both come from large families in which no one has a similar disability; we have no other children.

During the first few weeks of my pregnancy I was given Tetracycline and Provera. Ultrasounds up until six months showed normal fetal growth, but from seven months on, Dakota's head circumference started to drastically lag behind everything else.

My husband and I love our son very much and are desperately in search of some answers and a diagnosis. We would like to hear from anyone with knowledge of a similar child.

*W.J.R. & T.R.
New Jersey*

Filippi Syndrome

Our son Alec has been diagnosed with Filippi Syndrome (a growth disorder). Since this syndrome is very rare we are trying to obtain more information about it.

Filippi Syndrome is a genetic disorder which includes growth retardation, and low birth weight. The head and body are proportionate but below the third percentile. People with this syndrome also have fused toes, cleft palate, fusion of fingers three and four, inward curvature of the fifth finger, retarded bone age, mental retardation along with defective speech and language development and single palmar creases. They may or may not have a broad and prominent nasal root and diminished alar flare. These characteristics can range from severe to mild.

Other than our son, there is only one other reported case of this syndrome, and that family lives in Italy. If you have any information on Filippi Syndrome, or know of anyone that may have such information, please contact us.

*T.P.
Missouri*

Paroxysmal Choreoathetosis

Our five-and-a-half-year-old daughter has been diagnosed with a variant of a movement disorder called paroxysmal choreoathetosis. She was a very irritable infant; since about 12 months of age she has experienced an increasing number of uncontrolled movements that occur episodically. Each episode lasts one to two minutes, and she may have hundreds of episodes per day. These movements involve the upper and lower extremities, face, mouth and muscles of speech. There is no loss of consciousness. In between episodes, she has very delayed fine motor skills and moderately delayed gross motor skills. Her cognitive and social skills are unaffected. We have tried numerous medications without benefit.

We are searching for parents of children with similar difficulties, as well as professionals with a particular expertise in this disorder. Thank you!

*P.S. & D.S.
Minnesota*

Diabetes Insipidus

My now six-year-old son, Ryan, was diagnosed with a low-grade astrocytoma Level I-II brain tumor one month after his fourth birthday. He is now blind, although he has gotten back shadow and large form vision. Ryan also has diabetes insipidus, which causes him to be emotionally unstable at times, and causes him trouble with the regulation of his body temperatures.

I'm trying to find someone that also has these problems (especially the diabetes insipidus). Ryan doesn't know when he is hydrated or dehydrated, so I must weigh and measure all liquids that he ingests and passes. If you know of someone who has a child with these problems, please contact me.

*M.R.P.
Pennsylvania*

Editor's Note—For help getting in touch with other parents of children with diabetes insipidus, contact the Juvenile Diabetes Foundation International, 432 Park Ave. S., 16th Floor, New York, NY 10016, 1-800-533-2873, 212-889-7575.

Micro Deletion

My 19-month-old daughter, Emily, has a condition identified as a micro dele-

tion of 1 q. Offered. She is globally developmentally delayed and has agenesis of the corpus callosum. Is there anyone out there who has a child with this rare, unnamed syndrome?

S.T.
New York

F.A.S. and Multiple Impairments

I'm the adoptive parent of a three-and-a-half-year-old with multiple impairments. Andy has Fetal Alcohol Syndrome, is microcephalic, and is severely growth delayed. He has asthma, ADHD, spina bifida occulta with neurogenic bladder, and a mixed seizure disorder. He also has an undiagnosed "movement disorder" that causes constant tremors.

Andy is a loving, cuddly little boy. He is a lot of fun, but life with him is a roller coaster ride. I'm looking for pen pals with children with similar problems.

L.N.
Michigan

Child Hangs Head

My five-year-old daughter has cerebral palsy as a result of infantile spasms. She began pulling herself up to stand, walking around furniture and walking with assistance about seven months ago.

In the last few months, she has been "hanging" her head over the side of her walker, the backs of dining room chairs, her bed rails or anything she can find. Although she eventually

lifts her head back up, many times she does not do so until her face turns red and she needs air.

Recently, her doctor prescribed a soft collar to protect her throat and discourage her from hanging her head. Although she still is hanging her head, the collar makes the activity less intense.

I would like to hear from anyone who might be able to give us insight as to why our daughter does this and/or any ideas on how to help her overcome this problem.

K.L.H.
Louisiana

Parents Respond

Brain Injury at Birth

J.L. (April/May 1993) was searching for the "hope, wisdom and knowledge" to deal with her despair over her eight-month-old's disabilities, sustained as the result of a brain injury at birth.

Our little girl, Kaitlin, was born in August, 1992. She also sustained a brain injury at birth due to a knot in her umbilical cord—this is what we suspect, anyway.

Your letter really hit home because I also get very discouraged. Our daughter works hard and yet she's just starting to be able to sit. She was finally diagnosed with cerebral palsy at her one-year evaluation, yet somehow there are still so many unknowns.

We have found that we must ask a lot of questions and make sure that therapists tell us how to make our child's life better. We found that they did not give us much information unless we pushed.

You mentioned that you've lost faith in medical professionals. We have been lucky to have found some wonderful doctors, but we do ask for second opinions on certain issues. And I don't care whose feelings I hurt.

Our children are a wonderful blessing! Every time Kaitlin does something new, tears come to my eyes because I know how hard we have all worked!

I apologize for taking so long to write. I am just coming to terms with all of this. Please don't give up—our children need us!

K.R., Massachusetts

Irritability

B.A. (April/May 1993) was looking for suggestions after enduring two years of constant screaming and irritability from her child who has cerebral palsy. Due to this situation, the family was unable to go anywhere with the child.

I am a social worker, currently working in the Special Education Department of our local school board. When I read your letter, I was reminded of a discussion at a recent meeting of parents of exceptional children. Our guest speaker was the mother of a multi-challenged thirteen-year-old. She mentioned that when her daughter was young, she frequently screamed and had tantrums, particularly when they attempted social outings. Through contact with a professional, they learned that this child had highly sensitive hearing. As a result, she became greatly distressed in noisy public settings. Through the use of specially designed ear molds, the problem behavior completely ceased. After the speaker shared this information with the group, several other parents and professionals confirmed that hyper-sensitive hearing is often associated with various disabilities. Your letter immediately brought

this discussion to mind and prompted me to share this information in hopes that it may provide an answer to your prayers for "peace."

J.B., Louisiana

Adaptive Bike Carts

E.L.S. & D.S.K. (September 1993) were looking for a bike cart for their daughter who has multiple disabilities. She had recently outgrown her bike seat and her parents were looking for a new way to allow the family to continue enjoying bike rides together.

I am the parent of a 10-year-old boy with cerebral palsy. We also loved biking as a family until Brian outgrew conventional bike seats. This summer we purchased a *Bee Bop Kartsmobil*. The man who designed this is the parent of a child with special needs. We had seen this cart advertised in *Exceptional Parent* (see June 1993 issue, page 25). It attaches to the back of a bike. We place my son's Columbia car seat in it. He loves it! The address of the company is: Bee Bop, Inc., PO Box 9245, Yakima, WA 98907.

■ I have always loved bicycle riding too. However, my seven-year-old son, Julian, has cerebral palsy. Due to his poor balance, I never even considered a regular bicycle seat for him. Knowing that he would love riding, I searched long and hard for a solution.



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Here is a photo of Julian in his *Burley d'Lite* bicycle cart. I don't know if this would be appropriate for your daughter, but I can tell you that it is perfect for Julian and he absolutely loves it!

I bought this cart in a regular bicycle store. It cost \$350.00—which sounds like a lot of money—but considering how much use we get from it, it was worth every penny and more.

Julian's adaptive seat (Tumbleforms Carrie Seat) fits nicely into the cart, so he can sit comfortably and safely when alone. However, two children can fit in this cart so when Julian is riding with a friend, he sits in the cart without his seat.

Julian weighs about 35 pounds and his Carrie Seat weighs another 10

pounds. The maximum capacity of the cart is 100 pounds but I don't think I want to pull that much weight! The most I've loaded into the cart is about 70-75 pounds.

This cart has a number of features that I like. It is very stable with a low center of gravity so it cannot tip over. It is really easy to attach and detach from my bike. It is lightweight and collapsible (bike and cart fit in our station wagon). Julian faces forward, so I can keep an eye on him. There's even room behind the seat for groceries or lunch.

The company can be contacted at: Burley Design Corporation, 4080 Stewart Road, Eugene, Oregon 97402, 503/687-1644.

I probably sound like I work for the company. I don't! I just think this cart was so well-designed.

L.M.
New York

■ We take our six-year-old son for family bike rides all the time. It is one of the few things we can all do together. He has cerebral palsy and requires some special consideration when it comes to participating in

activities. He sits in his adaptive seat and then we put the seat in a bike cart made by *Cannondale*. We put a large Velcro® strap all around him and close it for safety. The cart attaches to the back of my husband's bike, and off we go.

You need to consider whether you need to see your child at all times. Do you want your child in front of the bike? Do you need to use covering? These are things to think about. We bought our Cannondale used at a local bike shop. We brought our son with us and tried him out in it before buying.

You can contact the company at: Cannondale Corporation, Georgetown, Connecticut 06829, 1-800-Bike-USA, 1-800/321-2821.

N.S.
Illinois

Blessed and Befuddled

J.C. (September 1993) feels blessed to have her 19-month-old daughter, Jordan Amanda, who has a physical disability. However, after a year of battling with insurance companies about the necessity of Jordan's physical therapy, she admitted to also feeling "befuddled" by the way the system works. J.C. wanted to hear from other parents who had fought these kind of battles, and suggested that a group of such parents might be able to achieve national attention for their struggles.

Our two-year-old son, Sean, currently attends physical therapy sessions on a weekly basis. As with your daughter, this is the only intervention prescribed. Sean has been in therapy for nine months. During that time our insurance company has paid 80% of these costs after we met our yearly deductible.

The only diagnosis we have for Sean is ataxia. It has been our experience that diagnosis is a key factor in dealing with the insurance company. Why don't you check with your neurologists to see if there could be another diagnosis that would fit Jordan and be acceptable to the insurance company?

Another option might be to check with local agencies to see what kind of programs they offer. United Way, Easter Seals or other organizations should be able to point you in the right direction. Most programs offered by these agencies are inexpensive and many are even free.

L.O.
Alabama

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We Hear You.

S E N T I E N T S Y S T E M S

TECHNOLOGY, INC.

■ I am also the mom of an exceptional child named Jordan. My son, Jordan, is three years old, has cerebral palsy, a controlled seizure disorder and microcephaly. He cannot respond to the typical cognitive testing methods, but I know he has much more intelligence than he's ever been given credit for. He was given an extremely dismal prognosis. The doctors explained the "horrendous" CAT scan, the "nearly flat" EEGs and all their other evidence that Jordan would never survive past a year of age and would be vegetative. He blew that prognosis out of the water in no time and has continued to progress despite the predictions of the "experts."

Jordan has had extensive therapy—OT, PT and ST sessions three times a week—since he was four weeks old. The baby who would never walk, talk, sit, eat or think is eating—he loves chocolate, can sit up with a little help, is learning to crawl, jumps around like crazy in his Johnny jumper and screams with delight when taken swimming. He is such a happy, good-natured, irresistible little guy who's loved so much and loves so much!

The frustration you feel is felt by all of us, and unfortunately your battles are just beginning. Take a deep breath, plant your feet firmly, and refuse to take "no" for an answer.

Whether it be therapy, equipment needs, schooling or anything else, you will be fighting for the rest of your life. No one else knows the potential of our children better than we, and they deserve to have us standing strongly and firmly in their behalf. I've always been a fighter; now I'm a professional fighter! Never stop and never give up when you are fighting for what your child needs and deserves.

As for going on national television—forget it! I once sent a very detailed letter full of ideas on doing a show about these children. I got a reply with a postcard saying the show's producers didn't feel this topic would be of interest to the viewing audience. So turn the TV off, and turn to people who will support you. Stand steadfastly in your child's corner and stay away from those who are uninformed and ignorant. They will never know how wonderful our kids are or how these truly exceptional children can touch hearts and lives forever.

M.K.
Illinois

Insensitivity of the Cornea

C.B. (September 1993), the parent of a five-year-old with VATER syndrome and insensitivity of the cornea, was looking for other parents with this eye condition.

Our one year old son was also born with VATER syndrome and, like your child, has insensitivity of the cornea. We had to even strap his arms to keep him from scratching his eyes at one point.

There are several different aspects of the VATER Syndrome, and I would like to know what my child and yours have in common. Our son has vertebral defects, T-E fistula with esophageal atresia, prenatal growth deficiency, and severe hearing loss.

I've had a lot of trouble finding information on VATER syndrome (sometimes called "VATER association") and would appreciate it if you could share any information that you find.

J.L.
Ohio

Cerebellum Hypoplasia

J.K. (September 1993) wanted to hear from other parents of children with cerebellum hypoplasia. J.K.'s 19-month-old son had been diagnosed with this condition, but is making more physical progress than doctors had predicted.

My two-year-old son, Lukas, has been diagnosed as having Dandy Walker malformation. However, doctors say his condition is unusual for Dandy Walker. Luke has hypoplasia of the right cerebellum and agenesis of the left cerebellum and vermis. Basically, he has very little cerebella tissue on the right side and none on the left. MRIs do not show a vermis.

At three weeks of age, Luke had an MRI. The neurosurgeon said that Luke's cerebellum was severely malformed but that the rest of Luke's brain was normal and that the small amount of tissue on the right side was normal.

We immediately enrolled Luke in early intervention—a therapist coming to our home once a week. He developed normally until he was about six months old, then started showing gross motor delays. He finally began walking at 22 months. He has balance problems and falls frequently, especially when distracted. He's having trouble with steps, and it appears that

he doesn't sense the location of his body in space.

Luke is typically very pleasant and has a mischievous personality. He loves to tease. In many ways he is a typical two-year-old.

Several doctors now doubt the Dandy Walker diagnosis, but have kept it because there is no other explanation. With Dandy Walker, the cerebellum is always affected, usually underdeveloped and typically missing about a third of the tissue from both sides. The tissue may or may not be normal. A cyst is usually present. There is no known cause.

For Luke, they now think what looked like a cyst may actually be just a collection of cerebral spinal fluid. You can't have empty space in the brain so since there was no tissue it is filled with fluid.

Another condition I have learned about is Joubert Syndrome. This often goes undiagnosed, or is misdiagnosed as Dandy Walker. With Joubert, the cerebellum can be affected and there is almost always hypoplasia of the vermis. Other features that help make this diagnosis are visual problems—usually nystagmus—breathing difficulties, tongue protrusion, low muscle tone and developmental delays. This is a genetic condition. They ruled it out for Luke. If you want more information about Joubert, contact the Joubert Syndrome Parents-In-Touch Network, Mary Van Damme, 12348 Summer Meadow Road, Rock, MI 49880.

It seems that, at least in physical development, your son and mine are similar. The medical literature paints a bleak picture and is very depressing, however, as I have learned from other parents, kids may have minimal to severe effects. Some children don't walk. Yet others play soccer or dance.

A pediatric neurologist in my community is a researcher in cerebellums. He told me that if one has to be missing a piece of brain, one should hope that it is the cerebellum. He feels because Luke has had this since birth, he will grow up learning to compensate. A congenital condition is much better than an injury to the cerebellum later in childhood. He said that people can do very well without cerebellums. The only long-range affect might be some physical clumsiness or awkwardness.

S.G.
Pennsylvania

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For more information on the Physically Challenged Assistance Program, call us at **1-800-255-9877**.

Health Care Reform:



To provide readers with a broad perspective on the proposed health care plan, we have excerpted relevant sections from the documents that were prepared by the Department of Commerce at the time the President's program was announced. It is particularly noteworthy that specific sections of these documents were devoted to disability issues.

The following are excerpts from The President's Health Security Plan, Preliminary Summary prepared by the National Technical Information Service of the U.S. Department of Commerce, September 22, 1993.

Benefits

The health benefits guaranteed to all Americans contain no lifetime limits on coverage, and provide a comprehensive package of medical services delivered in hospitals, clinics, professional offices and other sites. One uniform, comprehensive benefit package replaces hundreds of different insurance products on the market today.

When medically necessary or appropriate, covered services include hospital care, emergency services, preventive care, hospice care, home health and extended-care services following an acute illness, ambulance services, outpatient laboratory and diagnostic services, prescription drugs and biologicals, outpatient rehabilitation, durable medical equipment, vision and hearing care, periodic medical checkups and preventive dental services for children.

The plan includes coverage for a full range of preventive screening and care often not covered in traditional health insurance policies...

Additional benefits, including preventive dental care for adults and a more comprehensive mental health and substance-abuse benefit, are phased into the nationally guaranteed benefits by the year 2001...

What Does it Actually Say About Disabilities?

All individuals in a health plan pay the same premium for the nationally guaranteed comprehensive benefits regardless of health status, age, place of residence or employment status. Health plans are prohibited from discriminating based on existing medical conditions and other individual characteristics...

Long-term Care

...Disabled Americans of all ages gain access to a wider variety of home and community-based support services, making it possible to continue to live at home. The Health Security plan also provides the following expansions and improvements in coverage for long-term care:

- Improvements in Medicaid coverage for institutional care expand eligibility for nursing home coverage. The amount of income and assets Medicaid beneficiaries may retain increase to \$12,000 and the \$30-a-month living allowance rises to \$100.
- The establishment of national standards improves the quality and reliability of private long-term care insurance, while tax preferences encourages its purchase.
- Tax incentives also support the efforts of people with disabilities to work, covering 50 percent of their costs for personal assistance and other necessary support.

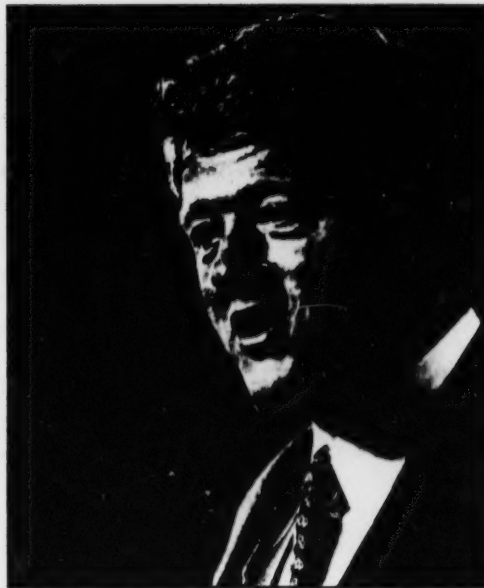
Medicaid

Medicaid recipients under the age of 65 who are not eligible for cash assistance either through Aid to Families with Dependent Children or Supplemental Security Income no longer enroll in Medicaid. They choose a health plan through their area alliance, with 80 percent of the premium covered by employer contributions if they are employed, or premium discounts if they are unemployed and have low incomes.

Medicaid continues to pay the cost of health insurance for recipients of AFDC and SSI, who also pick a plan offered by the regional alliance. They may choose any plan priced at or below the weighted-average premium without making additional payments...

...Health plans receive the same payment for Medicaid recipients as for other participants, reducing any stigma associated with obtaining coverage through Medicaid...

Medicaid coverage for other services, including nursing home coverage and special services for the severely disabled and supplemental services, continue as a public program.



Some Questions and Answers

Q: What happens if I change jobs? Will I risk losing health coverage?

A: No. The Health Security Act will guarantee that you will never lose your insurance coverage—even if you change jobs, lose your job, move, or start a small business. It will be illegal for insurance companies to drop you for any reason.

Q: What if someone in my family has a pre-existing health condition? Will they be covered?

A: Absolutely. Under the Health Security plan, it will be illegal to refuse to insure people just because they've been sick. Health plans will have to accept you—healthy or not—and, most important, they cannot charge you more for being sick.

And you'll have the security of knowing that no one can ever take your benefits away from you.

The following is excerpted from The President's Health Security Plan. Comprehensive Overview prepared by the National Technical Information Service of the U.S. Department of Commerce in September.

People With Disabilities: The Problem

Insurance Barriers

People with disabilities are presumed to be high health care users. Despite the fact that most are not sick, many are charged higher premiums, subjected to pre-existing condition exclusions, or rejected as unacceptable risks.

Disincentives to Employment

- People with disabilities face a limited range of job choices since smaller businesses are less likely to be able to afford coverage for them.
- When employed, people with disabilities are more likely to be locked into jobs, fearing loss of their insurance if they change jobs.
- The ongoing need for care in the face of limited insurance choices can force people with disabilities out of work in order to obtain coverage through Medicaid.

- Disabled individuals receiving public support often have a disincentive to work. The net value of income support (from SSI SSDI) bundled with publicly funded health insurance (from Medicaid and Medicare) often exceeds the income from a job.

Poor Long-term Care Coverage

- As many as one-third of those in need of long-term care are under age 65.
- Government programs that provide assistance for long-term care are biased toward institutional care rather than home and community-based care. People with disabilities often lack access to the community-based services they need.

People With Disabilities: The Health Security Plan

Insurance Reform

- People with disabilities will have access to the same health plans at the same price as the rest of the population. Insurance companies will no longer be able to deny them coverage or charge them higher rates because of their disability.

Prescription Drugs

- The comprehensive benefits package will include coverage of prescription drugs important to people with disabilities. Medicare will also be expanded to cover prescription drugs.

Long-term Care

- The Health Security plan will establish a significant new home and community-based care program, made available to all people with severe disabilities without regard to income—840,000 disabled Americans will now benefit from this new home and community-based program.
- Through the new home and community-based program, a broad range of personal assistance services will be available to children and working-age adults with severe disabilities regardless of income.
- For low-income persons with lesser levels of disability, states will be able to continue their home and community-based service program under Medicaid.

Tax Incentives to Obtain Employment

- Employed individuals who need assistance with activities of daily living and who purchase personal care and personal assistance services will qualify for a tax credit. ■

The Disability Community Reacts

President Clinton's address on September 22, 1993, was the first official description of his proposals for health care reform. Immediate reaction from the disability community was largely supportive of the President's general framework for reform. For example, the Consortium for Citizens with Disabilities responded on September 23, 1993, as follows:

"The Consortium for Citizens with Disabilities (CCD) strongly supports President Clinton's initiative in making health care reform a top priority for his Administration. We are pleased that for the first time an Administration is supporting comprehensive reform and has offered a proposal that finally addresses many of the problems in our current system.

"The CCD is a Washington-based coalition of over 100 national organizations concerned with disability policy, which advocates on behalf of people with disabilities. CCD member groups represent people with physical, mental, cognitive, and sensory disabilities and people with chronic, disabling illnesses. These individuals and their families are the most vulnerable in the present health care system. They have often been refused health insurance because of pre-existing conditions, have had to accept inadequate coverage, and have been most threatened by loss of coverage. Therefore, health care reform that will provide universal, comprehensive, and affordable health care to all Americans regardless of their health or disability status is a major priority of the Consortium.

"The CCD measures all reform proposals against five

principles for health care reform from the disability perspective. These are non-discrimination, comprehensiveness, appropriateness, equity, and efficiency. In many ways, the President's proposal measures up to the CCD principles. For example, the guarantee that no one will be denied health insurance for any reason and the elimination of pre-existing condition exclusions will mean that many people with disabilities will finally have access to health care services.

"Further, we are pleased that the proposal includes important new initiatives in the area of long term services and supports, including personal assistance services. Taken together with the acute health care reforms, these new initiatives are a critical step toward achieving independence, integration, and productivity for millions of Americans with disabilities and fulfilling the promise of the Americans with Disabilities Act.

"We strongly believe that President Clinton is proposing a system that would be a major improvement over what exists today. He is attempting to lay the groundwork for a universal system under which every American will have access to comprehensive health care regardless of their age, income or health

status...We oppose efforts to maintain the status quo in our health care system or to enact only incremental or marginal reforms. We applaud the President in this historic effort to enact comprehensive, universal health care coverage for all Americans, particularly those who need it most: persons with disabilities and chronic illnesses." ■

*Another Perspective —
Senator Robert Dole
shares his thoughts.*

page 22

So Far, So Good

As the statement by the Consortium for Citizens with Disabilities emphasizes, the President's plan offers dramatic changes that will make health care far more accessible to children and adults with disabilities. As we go to press in mid-October, knowing that our readers will not receive this issue for at least four weeks, we remain optimistic about this plan because it is clear that our leaders want to address health care needs as fully as possible, and that they have heard the needs of children and adults with disabilities and their families. Nonetheless, as parents and professionals have examined the fine details of the President's plan, they have raised some concerns.

- It appears that outpatient rehabilitation services—such as physical therapy, occupational therapy, speech and language therapy, counseling, psychotherapy and respiratory therapy—will be limited to individuals with needs caused by "illness and injury" (often called "acute" needs). The plan appears to omit outpatient therapies for children and adults with long-term needs that result from birth injuries or developmental conditions (often called "chronic" needs). Individuals with chronic needs often require such therapies in order to maintain and/or improve abilities, as well as to prevent future deterioration of abilities.
- It seems that so-called "durable medical equipment" (wheelchairs, seating systems, other mobility aids, etc.) will be covered only when such equipment is deemed a "medical necessity." This may exclude equipment that helps individuals become more independent—i.e., equipment that helps them to utilize technology, attend school or get to work. It also appears that so-called "customized equipment" (equipment designed to meet specific needs of an individual) may not be covered.

These are important concerns and we reiterate our October editorial message: write letters and speak out on these issues. At the same time, it is important to acknowledge that the two concerns noted above are serious shortcomings of present health care insurance and reimbursement programs. Very few current reimbursement programs cover either of these two needs, and parents must routinely choose between paying extra costs themselves or "making do" with less-than-optimal care or equipment for their children.

We commend the Administration and the Congress for taking on the monumental task of reforming our health care system. Elected officials and members of the general public are finally discussing these issues and coming to recognize that major changes are needed and that there are no easy solutions.

—S.D.K., K.S.

EXPAND YOUR HORIZONS

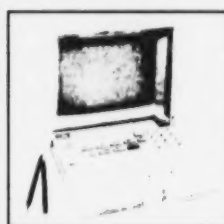
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Features 4 row keyboard, 20 character display, built in printer with upper and lower case printout. Options include auto-answer, keyboard dialing, clock/calendar, ASCII code.

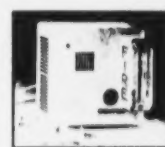


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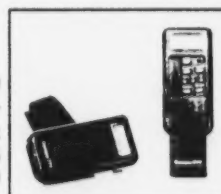


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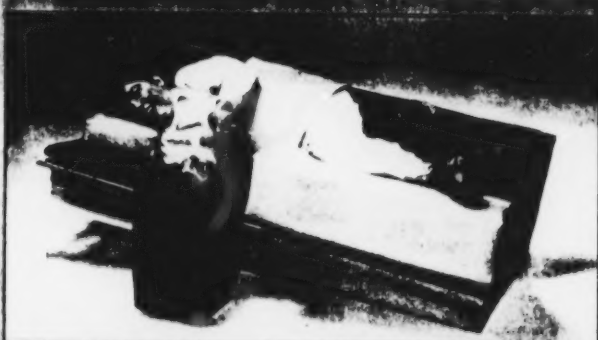
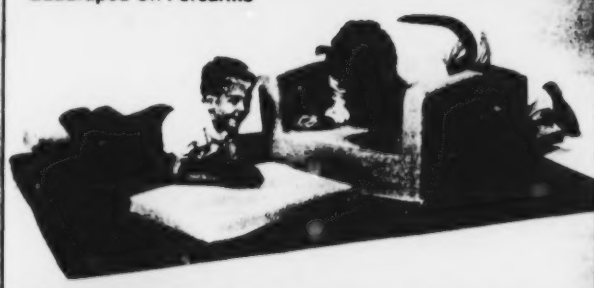


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Health Care Reform— Another Perspective



No doubt about it, the national dialogue on health care has begun. America is ready for reform. And for many obvious reasons, people with disabilities and those with chronic health conditions have a special stake. Indeed, there is perhaps no other group for whom health care reform holds such opportunity and peril.

All Americans want the peace of mind of knowing they're covered, and that they'll stay covered at an affordable price. And for those with disabilities who have stayed out of the job market in order to keep their Medicare or Medicaid, health care reform will hopefully mean they can look for work with the confidence they will be able to obtain other—and perhaps better—medical insurance. At the same time, we must see to it that the very jobs they will be seeking, often in small businesses, will not be lost because of the costs of health care mandates.

But, I also believe that people with disabilities, like most Americans, want to know that the quality, choice, and innovation that characterizes American health care will continue to be a reality. Indeed, for people with disabilities, choice often determines quality. Not all health providers—whether physicians or other health professionals—are knowledgeable about, or even comfortable with, providing health care to people with disabilities.

I also know that many people with disabilities are looking for coverage for services which today are not covered or only partly covered by many medical insurance plans. These things include personal assistance, long-term care, assistive technology, durable medical equipment and rehabilitation services. We can make no promises at this time except to say that we will give these matters careful consideration. But where such services are not provided by a basic benefits package, we will try to provide maximum flexibility for another means to make such services available—whether through optional plans or state programs.

At the very least we would not want people with disabilities to lose services they are already receiving, whether under a private plan, Medicaid, or Medicare. I encourage people with disabilities to look very carefully at any health care reform proposal in this respect.

—Senator Robert Dole

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Baking cookies: Two-year-old Eden Clements helps mom by stirring the cookie batter.

New Technology for Artificial Arms

Like most two-year-olds, Eden Clements jumps at the chance to help her mother bake cookies. When all the ingredients have been added to the large mixing bowl, she eagerly reaches out for the big wooden spoon Mom offers. It takes Eden a few seconds to get a firm grip on the spoon. A tiny motor whirs in her artificial right arm, making three of her fingers slowly open and close in response to electrical signals from muscles in her natural arm, which ends just below her elbow. Grasping the wooden spoon firmly with both hands, she begins to stir the thick batter.

The myoelectric option

Artificial arms with electric circuits that sense muscle signals can help some children with upper limb deficiencies to explore the world just like children who have two hands.

Electronic limbs, called myoelectric prostheses, come close to imitating the function of normal human arms and hands. Children who wear this type of prosthesis can touch their index and middle fingers to their thumbs. With practice, they can learn to control muscle impulses to vary the strength of their grasp, even though they cannot feel how hard they are squeezing.

Hook prostheses are a less advanced option. This type of artificial arm has two metal hooks for grasping. The hooks are controlled by a metal cable attached to a harness worn around the shoulders. The position of the shoulders controls the tension on the metal cable, causing the hooks to open. Rubber bands positioned around the base of the hooks force the hooks to close when the wearer allows tension on the cable to subside. Children who

use this type of prosthesis cannot grasp objects that are above the head or behind the back.

Myoelectric limbs are more versatile. Children who use a myoelectric limb rather than a hook-and-harness prosthesis, can better control the strength of their grasp because the fingers stop moving when the electrical signals cease. The myoelectric limb can grasp objects regardless of the wearer's shoulder position. And some children with upper limb deficiencies can use the prosthesis even if they have weak shoulder muscles or no shoulder at all.

Electrodes transmit nerve signals

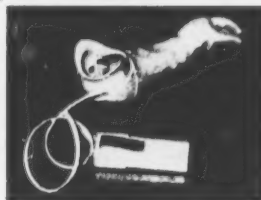
Typically, two electrodes are nested in the socket of the myoelectric arm. The electrodes, pieces of metal that detect and transmit electrical signals, rest on the skin of the residual limb, near muscles naturally responsible for opening and closing the hand. The nerves in these muscles send out electrical signals when the muscles flex and contract. The electrodes transmit these electrical signals to a signal processor and battery-powered motor in the artificial limb that tells the fingers to move.

If muscles in the affected upper limb are weak, other muscles in the body can control the prosthesis. For example, electrodes at the end of a long wire can transmit electrical signals from back muscles to a myoelectric arm. A child can learn to move these muscles to operate the prosthesis.

A myoelectric limb looks more natural than other prostheses. For a child who has an arm that ends just below the elbow, a hard plastic sleeve molded to match the contour of the elbow holds a removable custom-made socket in place. In addition to the electrodes, the socket contains a motor and, usually, its rechargeable battery. If the artificial arm is too bulky, the battery is attached to the motor by a thin wire and pinned inside the child's clothing. A hand with five fingers, covered by a replaceable soft vinyl glove, attaches to the socket. The glove, which needs to be replaced two to three times each year due to wear and tear, has nail beds that can be painted and comes in various shades to match the child's skin tone.

Myoelectric Below-Elbow Prosthesis for a Young Child

Component	Average time between repairs/refittings
Socket	18 months
Growth liners*	10-12 months
Hand	2-3 years
Glove	4-6 months
Battery	1 year (requires daily recharging)
Battery Charger	Indefinite



* A "growth liner" is a socket insert, or a socket within a socket. Each growth liner can extend the life of a socket by approximately four to six months. When the prosthesis becomes too snug, the growth liner can be removed so that the prosthesis fits the child for a little bit longer.



Some professionals believe that children who can benefit from a myoelectric prosthesis should begin wearing this type of artificial arm around their first birthday. (Photo courtesy of Variety Myoelectric Center, Rehabilitation Institute of Michigan.)

Because the function and appearance of myoelectric prostheses closely resemble natural arms and hands, they often escape notice. People's initial impression of Eden is that she is a child like any other and they treat her accordingly, says her mother, Peg Bradshaw. By the time they realize that she has an artificial arm, Bradshaw says, it's too late to treat her differently.

Fit early or wait?

Some professionals believe that children who can benefit from a myoelectric prosthesis should begin wearing this type of artificial limb around their first birthday. They argue that early use of the prosthesis offers advantages that would not be possible at four or five years of age. Very young children quickly learn to compensate for the weight and sensation of an artificial arm. They learn to sit up, play with toys and dress themselves with two hands. Children who are not fitted with prostheses until after mastering such basic tasks are used to working with one hand and may be less motivated to use the artificial limb.

Other professionals say that fitting children at such a young age is a waste of money. They argue that toddlers quickly outgrow sockets and hands. One of Eden's prostheses, used for only seven months, cost \$6,000. In Ontario, Canada, where Eden and her mother live, the Provincial health insurance program covers the expense. But the boost to Eden's self-esteem and her ability to fit in with other children would make any cost worthwhile, according to Ms. Bradshaw.

For children fitted at a young age, prosthesis use can become quite natural. Eden began using a myoelectric

prosthesis when she was 11 months old. At first, her mother had to nudge her to take advantage of the artificial arm. Now, less than one-and-a-half years later, Ms. Bradshaw does not even remind her. Eden wears her prosthesis when she eats and naps. Unprompted, she reaches for objects with her artificial rather than her natural hand.

Not for everyone

But myoelectric prostheses are not appropriate for all children with limb deficiencies. Children who have two or more natural fingers on an affected limb are better off using their natural fingers, which can feel heat, cold and pressure. If a child has poor muscle tone, it may not be possible to find muscles that can send signals strong enough to control the prosthesis. Children with two affected arms may benefit from the faster motion of the hook prosthesis. And those who want a natural-looking arm but are not interested in using it to reach or grasp would be better served with a passive prosthesis—an artificial arm that has hair, nail beds that can be painted and a more natural shape.

Although myoelectric prostheses cannot help all children with limb deficiencies, they can help many to explore the world with two hands—just like everyone else.

P.C.C.

Special thanks to Eileen Mason-Wilhelm, service line manager of Amputee Services at Rehabilitation Institute of Michigan in the Detroit Medical Center, for providing information for this article.

Some Pediatric Amputee Programs that Fit Children with Myoelectric Prostheses

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Takeshi Sakuma has arthrogryposis. Because he has limited movement, he finds it difficult to use a standard computer keyboard. Here he is using an alternative keyboard from Intellikeys. Takeshi, a first-grader in a Berkeley, California, public school, has used IBM, Apple, and Atari computers. He is considered the "computer expert" by other members of his Users Group—the Disabled Children's Computer Group. (Photo courtesy of Intellikeys.)

Getting Started with Computers

*by Madalaine Pugliese
and Bill Davey*

Exceptional Parent has been publishing annual technology issues for eleven years—strong evidence that **assistive technology*** has already had a significant impact on the lives of children with disabilities. But for every parent who has become computer-literate and kept up with the latest technological advances, many others feel that the technology revolution has left them behind. How can a parent begin to navigate the maze of current microcomputer technology? What can a child with disabilities do with computers? What do you need to get started? Who can answer your questions, and, more importantly, what questions should you ask? If you've just begun pondering the ways that computers might help your child, this article may be a good place to start.

Purchasing your first computer

Buying your first computer is like making any major purchase—even if someone in the family has special computer-access needs. When shopping for a new television or kitchen appliance, you begin by considering the features you want this new purchase to offer. To learn more about available options, you may read consumer publications, visit retailers just to "look around," and make comparisons to get the best deal possible.

When contemplating a computer purchase, you should visit a few computer stores to try them out for yourself, learn about what comes standard with each system, and determine any extras you might wish to purchase. You should not expect computer sales people to address adaptive access issues. Those questions can be addressed by someone else later. You should, however, expect the sales person to know about computers. If this person cannot help you understand your computer needs, keep shopping for the right person to assist you.

*Words and phrases printed in bold italic are defined in the glossary on page 32.



Bountavie Cbeam, who has Down Syndrome, accesses the computer by using a touch screen made by Edmark. (Photo courtesy of Edmark.)

A computer salesperson will probably begin by asking what you want to do with a computer. This is something to think about before you start shopping around. You might already have some specific goals in mind; other ideas might come from reviewing this article. When the salesperson knows your interests, he or she can suggest **hardware** and **software** that will meet your needs.

Machine compatibility between home and school will be the most important factor for many families. If your child's school program uses a certain type of computer, it will probably be most helpful for the child if the same kind is available at home.

What about optional equipment?

Once you've chosen a basic computer system, it's time to think about adding some "extras." Not all options are truly optional; many people consider the following add-ons to be essential:

- A color **monitor** is usually desirable for running educational software and computer games. Color distinctions are often integral to understanding the lesson or game. And even if color is not an essential part of the program, software run on a monochrome (black and white) monitor may not hold a child's attention as well.
- A **printer** is useful for documenting and sharing a child's work. A child who is unable to hold a pencil and write a letter to Grandma can use the computer and printer to accomplish the same goal.
- A **hard disk** is also recommended because you can use it to store many software programs, eliminating awkward and time-consuming **floppy disk** swapping.

Take Control!

Many children and adults with disabilities begin exploring the wonders of computers and assistive technology during a visit to an *Abilities Expo*. These large consumer showcases for products and services for people with disabilities are held annually at a number of sites across the U.S. Since 1990, Adaptive Rehabilitation Technology, Inc., a nonprofit organization, has presented an adaptive computer lab, *Take Control!*, as part of every Expo event. Visitors to the *Take Control!* lab have the opportunity to try out adaptive devices and software with the expert guidance of experienced specialists, product manufacturers, other users with disabilities and public or resource agency representatives.



Madelaine Pugliese of Adaptive Rehabilitation Technology, Inc., works with a young visitor to the Take Control! adaptive computer lab at a recent Abilities Expo. The two are using a touch screen.

Upcoming Abilities Expos*

Dallas, TX at the Infomart	December 3-5, 1993
Orlando, FL at the Omni Centroplex	January 14-16, 1994
Edison, NJ at the Raritan Center Expo Hall	April 15-17, 1994
Anaheim, CA at the Anaheim Convention Center	May 20-22, 1994
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- If you expect to use "talking" software, check to see if your computer already "talks." If not, you'll need to add a **speech synthesizer**.

- You might also consider adding a **modem** that allows your computer to send and receive information through telephone lines. Through telecommunications, children may develop friendships with "pen pals" in other parts of the country or the world. A modem also enables older children or adults to play on-line games, tap into research sources such as on-line encyclopedias, check current news or weather reports and use other information services.

The "right" time to buy

Deciding when to buy a computer can be particularly frustrating. Industry conditions change so rapidly that you might find a "better deal" a week after you bring your new computer home. On the other hand, there is a tendency for people to wait so long for a price to drop or a new option to become available that they never get around to actually making a purchase. Meanwhile, a child who can benefit from the technology waits. The important issue is that you end up with the features you need and can access solutions that work for you. Just as a new car depreciates dramatically the minute you drive it off the lot, your new computer will probably be "outdated" before you can possibly master all its useful options. That's just the way it is—so try to relax, go ahead and get started! You can always trade up later.



Keith P. Jones, who has cerebral palsy, began using computers by typing with his toes. This process was slow and tedious; aides had to write out his homework for him so he could get it done in time. A Kurzweil Voice Input System now allows Jones to speak into a microphone and see his words appear in written form on the screen. "It makes me feel more independent," he says. "It makes my work ten times easier, and it's better because I get to do it myself." (Photo courtesy of the Boston Public Schools Special Education Technology Center.)

Where to buy

If money is the only concern, mail order and volume discounters are the least expensive sources for both hardware and software. This path should be taken only by buyers who know exactly what they need, however, as mail order suppliers and discount stores are unlikely to be consistent sources of helpful advice. Prices may be higher at a small, local computer store, but higher prices can be worth it if your purchase comes with before-the-sale counsel and after-the-sale support.

Learning to use your new computer

Local adult education programs often offer a surprising variety of computer courses for beginners. This can be a wonderful and inexpensive place to start. Local computer user groups may also offer beginners' workshops. You can obtain information on user groups from local computer stores or libraries. User groups offer a great way to meet other computer users—both novices and those with more experience.

Whether you begin with a computer class or workshop, be sure to ask lots of questions. Many beginners feel foolish asking what seem like elementary or simple questions. Don't make that mistake—ask all the "ridiculous" questions that come to mind. The more you ask, the more you'll learn and understand.

Finally, practice as much as you can. It's amazing how much you can learn about your computer just through "fooling around" with its various features. As with any new skill, the more you practice, the quicker you will become proficient.

Planning for adaptive access

When children are given access to computers, their self-confidence and potential can change dramatically. Fortunately, today's assistive technology resources are plentiful. First, turn to the professionals that currently provide services to your child. This might include speech therapists, occupational therapists, physical therapists and other specialists. Ask for their assistance with such issues as appropriate seating and positioning for the child and equipment, or ways of gaining access to the **keyboard**. Professionals who are already familiar with your child's strengths may readily offer suggestions on ways to access the system. A formal evaluation might also be useful to answer some access questions. The child, however, will be your most valuable advisor on access issues; he or she will let you know—in no uncertain terms—what does and does not work.

Several resources for investigating adaptive computer devices are available. Your nearest Alliance for Technology Access (ATA) center may be the best place to start. A state-by-state directory, following this article, lists ATA center locations and services offered by each. An ATA center is the perfect place to ask such questions as "Can I really control the computer with my voice?," "Where can I get a keyboard with bigger buttons?," "What do I do about the **mouse**, if I type with a pointer?," or "What software would be most helpful for me?" Other local community resources may include the Easter Seals Society or United Cerebral Palsy Association programs.

Alternative devices for computer input

There are plenty of "low-tech" ways to adapt standard computer input devices to meet your child's needs. Keyboard stickers with large symbols can help direct the child to the right key. Keyguards—plastic or metal keyboard covers with holes over each key—can be even more helpful in directing fingers or pointers and preventing accidental key presses.

An alternative keyboard may be more appropriate for some children. Alternative keyboards differ from standard keyboards in the size and separation of the keys, or their position and arrangement. Some alternative keyboards work only with specific software, while others work with any software—check before you buy. In some cases, a child's portable **augmentative communication** device can also serve as a computer keyboard so buying an alternative keyboard may be unnecessary.

Other children may have more success bypassing the keyboard completely. Some of these children may be able to use a touch screen. With a **touch screen** mounted over the monitor's display window, a child can communicate his choices directly to the computer by touching various parts of the screen.

Due to physical limitations, some children may not be able to use an adapted keyboard or other method of "direct selection." If a child has some limited but reliable movement, however, he or she can use a single **switch** for computer control. Some software programs are designed to be used with switches, and respond to the press of a switch rather than the keyboard.

Standard software can also be used with a single switch but will require some adaptation. To run standard software, you'll need a way to allow a switch press to send the same signal as a key press on a standard computer keyboard. "Scanning" is one way to accomplish this type of "keyboard emulation." Scanning is a process in which keyboard choices are displayed on the screen and highlighted one-by-one. The child presses the switch when his choice is highlighted. This has the same effect as pressing that key on the regular keyboard; the software doesn't know the difference.

Alternative devices for computer output

For children with visual impairments, the screen image can be enlarged. A Braille embosser can be attached to the computer like a standard printer, or a Braille display can replace the monitor. A speech synthesizer or the computer's own internal speaker can transform printed text on the screen to spoken words.

The computer's ability to "talk," along with a wide range of adaptive software, also allows a child who is non-verbal to use the personal computer as a vocalizing communication aid. Vocabulary and access can be adjusted for individual users. For example, a child who uses a pointing board and symbols for everyday communication could have the same symbols on a touch screen. The computer could speak single words or full sentences as the child touches each symbol.

Software adaptations

The family computer can offer increased social and recreational opportunities to children with disabilities by giving

them equal access to the same play environment as siblings and peers. Interaction among children who need support in working or playing together can be enhanced by selecting software that encourages cooperative goals, rather than competition.

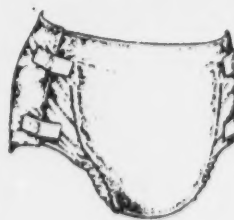
For recreational software that more than one child will use, it is helpful to find games that adjust to the performance of each player, so children can compete more equitably. This is not always easy. Parents have to preview the software and look for ways to accomplish "equalization." Some games will allow players to use input devices other than the keyboard. Others may allow you to "alter" the conditions of the game—slowing it down or allowing certain players to have additional turns.

Many families also use a home computer to help their children develop new skills and reinforce lessons taught in school. The computer, along with the right software, can create an ideal environment for practicing academics, memory skills, and general daily living skills. The computer is infinitely patient, and reinforces desirable responses with perfect consistency. Whether skill-building software is being used for enrichment or remedial purposes, learning or practicing new skills is more fun and effective using technology tools.

The ability to "alter" software features is important whether the software is intended for family recreation or learning. Your nearest ATA center may be able to recommend a few titles to get you started. Another idea is to put your name on lists to receive catalogs from mail-order software companies. Order titles that look attractive, and preview them in your own home. If you find that you cannot alter the software to meet your needs, just send it back.

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Just do it!

Delving into any new area of expertise can be scary. But the revolution in adaptive computer technology is too exciting to ignore. Technology can open a world of opportunity and access to many children with disabilities. So go ahead—take a deep breath and take the plunge. You'll be happy you did.

Madalaine Pugliese and Bill Davey are co-directors of Adaptive Rehabilitation Technologies, Inc., a non-profit information and outreach service promoting education, support and public awareness of adaptive technology. Madalaine holds Masters Degrees in Curriculum Design, Special Education and Educational Technology, and is a former director of the Special Education Technology Resource Center for the Boston Public Schools. Bill has been involved in adaptive computer access since 1982, and has worked with Closing The Gap and the Minneapolis Society for the Blind.

Glossary

Assistive technology—devices used by children and adults with disabilities to compensate for limitations and to enhance and increase learning, independence, mobility, communication and environmental control.

Augmentative communication device—usually, a portable electronic device that enables individuals who are unable to speak to use a synthetic voice. Such devices allow a user to select from pictures, words or sentences. When a selection is made, the device "speaks" a pre-programmed message.

Disk drive—a device to "read" information from or "write" information onto a disk.

Floppy disk—a flexible, flat, plastic plate with a magnetic coating that is covered with a protective jacket. Floppy disks vary in size (depending on the type of computer) and storage capacity, and are used for storing computer data.

Hardware—the actual computer and its associated devices (e.g. printer, modem, external disk drive, etc.). Devices which are separate from the computer itself are referred to as *peripherals*.

Hard disk—a rigid magnetic disk that is used for storing computer data. A hard disk is installed permanently within its own disk drive unit. It may be built into the computer or it may be a separate unit. A hard disk operates at high speeds and can hold hundreds of times more data than a floppy disk.

Keyboard—an input device that has keys like a typewriter with additional keys for special functions.

Modem—a device that converts computer signals into signals that can be transmitted over telephone lines.

Monitor—a television-like device that accepts video signals from a computer and displays pictures and words on a screen. A *color monitor* is capable of displaying information in a variety of colors, while a *monochrome monitor* can display only the same range of grays as most black & white televisions.

Mouse—a hand-held input device that, when rolled along a flat surface, controls the movement of a pointer on the screen. Pressing a button on the top of the mouse signals the computer to perform an action.

Printer—an output device that produces a paper copy of what is seen on the screen.

Software—computer programs that allow the computer to perform various tasks (e.g. word-processing, playing games, creating graphics, etc.).

Speech synthesizer—an output device that transforms typed or printed text into spoken words.

Switch—an input device that allows the user to transmit information to the computer with a single physical movement.

Touch screen—an input device that transmits information to the computer when the user touches various areas of the screen.

Something for everyone

Once you get your family computer all set up and running, you'll probably wonder how you ever got along without it. While each family member will find important individual uses for the machine, many families also find that the computer provides new ways for family members to work and play together. The entire family might make holiday greeting cards or posters for a weekend yard sale. Dad and the kids might use record-keeping software to organize their stamp collection. The kids might work together to create a giant "Happy Birthday" banner for Mom's birthday.

Computers can be especially beneficial for families who have a child with a disability because they can provide ways for the child to interact with siblings and peers on a meaningful, equal level. A child who can blink her eye can operate an infrared switch to have a computerized "pie fight" with her brother—just remember to duck in time! With a toe operated joystick, another child has enough control to run sophisticated music composition software, blast it out of the amplifier and jam with his pals in the garage—until Mom tells them to turn it down!

Many families will find that the home computer quickly becomes a possession that everyone in the family comes to treasure. For the child with special needs, however, the computer can be especially valuable. Many children with disabilities experience growth in social skills, thinking skills and self esteem with the use of computers. Most importantly, they often experience a new sense of control. Even though they may use a different way of accessing the computer, they are still using the equipment to accomplish their own goals and intentions.



Michael and Glenn share a computer activity. Michael takes his Macintosh PowerBook to school everyday. For better access, he uses an alternative keyboard made by Don Johnston, Inc., that fits over the notebook-sized Macintosh. He also uses a keyguard designed to fit this alternative keyboard. Both boys have cerebral palsy. (Photo courtesy of Don Johnston, Inc.)

Alliance for Technology Access Centers

The Foundation for Technology Access (FTA) began in 1987 as a joint project of a grass-roots organization—Disabled Children's Computer Group—and a major corporation—Apple Computer. From a small group of parents, consumers and professionals, FTA has grown to become one of the nation's largest resources for helping adults and children with disabilities gain access to the benefits of adaptive technology.

FTA's most important means of promoting technology access may be its Alliance for Technology Access (ATA), a nationwide network of community-based assistive technology resource centers. ATA centers work with a wide variety of individuals and organizations and have no eligibility criteria for determining who may receive services. Most centers provide hands-on consultations and product demonstrations, make recommendations and referrals, and present workshops on technology use. Individual centers may also offer additional services. The following pages provide an up-to-date directory of ATA centers, with a description of the specific services offered by each. (Services are coded by number. See key.)

ALABAMA

Birmingham Alliance for Technology Access Center
Birmingham Independent Living Center
206 13th Street South
Birmingham, AL 35253-1317
Phone: (205) 251-2223 0863
Fax: (205) 251-0605
AppleLink: BILC
1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 14, 15, 16, 17

Technology Assistance for Special Consumers

P.O. Box 443, Huntsville, AL 35801
Phone: (205) 532-5996
AppleLink: TASC
1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 14, 16, 17

ALASKA

Alaska Services For Enabling Technology
P.O. Box 6485, Sitka, AK 99835
Phone: (907) 747-3019
AppleLink: ASET.SE
1, 4, 8, 16

Key

- 1 Hands-on computer demonstrations
- 2 Guided exploration and technical consultations
- 3 Technical assistance to employers
- 4 Equipment, software and video loans
- 5 Family support and advocacy
- 6 Computer camps
- 7 After-school programs
- 8 Public events and presentations
- 9 Minority and low-income outreach
- 10 Adapted toy programs
- 11 Toy library
- 12 Workshops
- 13 User Groups
- 14 Early intervention services
- 15 Transition training for young adults
- 16 Technical support services
- 17 Professional development

ARKANSAS

Technology Resource Center
c/o Arkansas Easter Seal Society
2801 Lee Avenue
Little Rock, AR 72205
Phone: (501) 663-8331
Fax: (501) 660-1057
AppleLink: TRC
1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 13, 14, 15, 16, 17, team evaluations for augmentative communication, computer access, environmental controls, augmentative communication camp

CALIFORNIA

Computer Access Center
1807 Wilshire Blvd., #202
Santa Monica, CA 90403
Phone: (310) 829-6395
AppleLink: CAC.SM
1, 2, 3, 4, 5, 7, 8, 9, 12, 13, 14, 15, 16, 17

DCCG - Technology Resources For People with Disabilities

2547 8th St., 12-A
Berkeley, CA 94710-2572
Phone: (510) 841-3224
Fax: (510) 841-7956
AppleLink: DCCG
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 14, 16, 17, works on contractual basis with local school districts for individual students

Foundation for Technology Access

1128 Solano Avenue
Albany, CA 94706
Phone: (510) 528-0747
Fax: (510) 528-0746
AppleLink: FTA
3, 8, 9, 12, 11, 15, 16, 17, national general information center

Sacramento Center for Assistive Technology

Mather Heights Elementary School
Rancho Cordova, CA 95655-3399
Phone: (916) 361-0553
Fax: (916) 399-5366
AppleLink: SCAT
1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17

Special Awareness Computer Center

Rehabilitation Unit North
2975 North Sycamore Drive
Simi Valley, CA 93065
Phone: (805) 582-1881
AppleLink: SACC
1, 2, 3, 4, 5, 7, 8, 9, 12, 14, 16, 17

Special Technology Center

590 Castro Street
Mountain View, CA 94041
Phone: (415) 961-6789
Fax: (415) 961-6775
1, 2, 3, 5, 8, 9, 12, 14, 16, 17

Team of Advocates for Special Kids

100 W. Cerritos
Anaheim, CA 92805-6546
Phone: (714) 533-TASK
Fax: (714) 533-2533
AppleLink: TASK
1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 14, 15, 16, 17

FLORIDA

Computer CITE

215 E. New Hampshire St.
Orlando, FL 32804
Phone: (407) 898-2483
Fax: (407) 895-5255
AppleLink: CITE
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17

GEORGIA

Tech-Able

1040 Irwin Bridge Road
Conyers, GA 30207-4323
Phone: (404) 922-6768
Fax: (404) 922-9813
AppleLink: TECHABLE
1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13, 14, 16, 17, Braille printer and scanner available

HAWAII

Aloha Special Technology Access Center

1750 Kalakaua Avenue #1008
Honolulu, HI 96826-3725
Phone: (808) 955-4464
Fax: (808) 955-4464
AppleLink: ALOHASTAC
1, 2, 3, 4, 5, 8, 9, 10, 12, 14, 16

ILLINOIS

Northern Illinois Center for Adaptive Technology

3615 Louisiana Road
Rockford, IL 61108-6195
Phone: (815) 229-2163
Fax: (815) 229-2120
AppleLink: ILCAT
1, 2, 3, 4, 5, 8, 9, 12, 13, 14, 15, 16, 17, information referral for nine northern Illinois counties

Technical Aids & Assistance for the Disabled Center

1950 West Roosevelt
Chicago, IL 60608
Phone: (312) 421-3373
Fax: (312) 421-3464
AppleLink: TAAD
1, 2, 3, 4, 5, 7, 8, 9, 12, 13, 14, 15, 16, 17

INDIANA

Assistive Technology Training and Information Center

3354 Pine Hill Drive
P.O. Box 2441
Vincennes, IN 47591
Phone: (812) 886-0575
Fax: (812) 882-3575
AppleLink: ATTIC
1, 2, 3, 5, 8, 9, 10, 11, 12, 13, 14, 15, 16, rural outreach center for training parents on federal and state education, curriculum adoption, inclusion

KANSAS

Technology Resources and Solutions for People

3023 Canterbury
Salina, KS 67401
Phone: (913) 827-0301
Fax: (913) 827-5446
AppleLink: TRSP
1, 2, 3, 4, 5, 7, 8, 10, 11, 12, 14, 16

KENTUCKY

Blue Grass Technology Center for People with Disabilities

169 N. Limestone
Lexington, KY 40507
Phone: (606) 255-9951
Fax: (606) 255-0059
AppleLink: BLUEGRASS
1, 2, 3, 4, 5, 8, 10, 11, 12, 14, 16, 17, "Agrability" program provides technology to farmers and families

Disabled Citizens Computer Center

Louisville Free Public Library
301 York Street
Louisville, KY 40203-2257
Phone: (502) 574-1657
Fax: (502) 574-1671
AppleLink: DCCC
1, 2, 3, 5, 8, 9, 10, 11, 12, 14, 15, 16, 17

FTA-Eastern Support Center

1531 Dawn Drive
Louisville, KY 40216-1617
Phone: (502) 449-0645
Fax: (502) 449-0645
AppleLink: GLASS
East coast technical assistance office for people who want to start ATA centers in their communities

SpecialLink

36 W. 5th Street
Covington, KY 41011
Phone: (606) 491-2464
Fax/TDD: (606) 491-2495
AppleLink: SPECIALINK
1, 2, 3, 4, 5, 8, 9, 10, 11, 12, 13, 14, 16, 17

LOUISIANA**CATER-Center for Adaptive Technology and Educational Resources**

4323 Division Street, Ste. 110-B
Metairie, LA 70002-4179
Phone: (504) 888-5248, 888-0163
Fax: (504) 286-5588
AppleLink: CATER
1, 2, 4, 5, 7, 8, 9, 10, 12, 15, 16, 17

MAINE**Maine Parent Federation**

P.O. Box 2067
August, ME 04338-2067
Phone: (207) 582-2504
Fax: (207) 582-3638
AppleLink: MPF 5, 9, 12, 16

MARYLAND**Learning Independence Through Computers, Inc.**

28 E. Ostend Street, Ste. 140
Baltimore, MD 21230
Phone: (410) 659-5462
Fax: (410) 539-2087
AppleLink: LINC
1, 2, 3, 4, 5, 6, 8, 9, 10, 12, 14, 16, 17

MASSACHUSETTS**Massachusetts Special Technology Access Center**

12 Mudge Way 16
Bedford, MA 01730-2148
Phone: (617) 275-2446
AppleLink: MASTAC
1, 2, 3, 5, 6, 8, 10, 11, 12, 13, 16, 17
software lending library, classes,
referral services, newsletter

MICHIGAN**Living & Learning Resource Ctr.**

Physically Impaired Assoc. of Mich.
601 W. Maple Street
Lansing, MI 48906-5038
Phone: (517) 487-0883
(800) 833-1996 (MI)
Fax: (517) 371-5898
AppleLink: LLRCPIAM
1, 2, 3, 4, 8, 9, 12, 14, 16, 17

MINNESOTA**PACER Center, Inc.**

4826 Chicago Avenue South
Minneapolis, MN 55417-1055
Phone: (612) 827-2966 Voice TDD
Fax: (612) 827-3065
AppleLink: PACERCTR
1, 2, 3, 4, 5, 8, 9, 10, 12, 13, 14, 15, 16, 17

MISSOURI**Technology Access Center**

12110 Clayton Road
St. Louis, MO 63131-2599
Phone: (314) 569-8404 8100
(800) 735-2466
Fax: (314) 993-5957
TTY: (314) 569-8400
AppleLink: TACSTL
1, 2, 3, 4, 5, 6, 8, 12, 15, 16, 17

- 1 Hands-on computer demonstrations
- 2 Guided exploration and technical consultations
- 3 Technical assistance to employers
- 4 Equipment, software and video loans
- 5 Family support and advocacy

MONTANA**Parents, Let's Unite for Kids**

1500 N. 30th Street
Billings, MT 59101-0298
Phone: (406) 657-2055
Fax: (406) 657-2061
AppleLink: PLUK
1, 2, 3, 4, 5, 7, 8, 9, 10, 12, 13, 14, 15, 16,
17, IEP support

NEW JERSEY**Computer Center for People with Disabilities**

c/o Family Resource Associates, Inc.
35 Haddon Avenue
Shrewsbury, NJ 07702-4007
Phone: (908) 747-5310
Fax: (908) 747-5936
AppleLink: CCDA
1, 2, 5, 7, 8, 9, 10, 11, 12, 14, 16, 17,
Saturday pre-vocational program
for teenagers

The Center for Enabling Technology

9 Whippany Road
P.O. Box 272
Whippany, NJ 07981-0272
Phone: (201) 428-1455
AppleLink: CET
1, 2, 5, 8, 9, 12, 13, 15, 16, 17

Key

- | | |
|------------------------------------|---|
| 6 Computer camps | 12 Workshops |
| 7 After-school programs | 13 User Groups |
| 8 Public events and presentations | 14 Early intervention services |
| 9 Minority and low-income outreach | 15 Transition training for young adults |
| 10 Adapted toy programs | 16 Technical support services |
| 11 Toy library | 17 Professional development |

NEW YORK**Techspress**

Resource Ctr. for Ind. Living
409 Columbia St., Utica, NY 13502
Phone: (315) 797-4642 voice TDD
Fax: (315) 797-4747
AppleLink: TECHSPRESS
1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, early intervention transition

NORTH CAROLINA**Carolina Computer Access Ctr.**

Metro School
700 East Second Street
Charlotte, NC 28202-2880
Phone: (704) 342-3004
Fax: (704) 342-3004
AppleLink: CCAC
1, 2, 3, 4, 5, 6, 8, 9, 12, 14, 16, 17

NORTH DAKOTA**Pathfinder Parent Training and Information Center**

ATA Computer Resource Center
1600 2nd Avenue, S.W.
Minot, ND 58701
Phone: (701) 852-9426 9436
Fax: (701) 838-9324
AppleLink: PATHFINDER
1, 2, 4, 5, 7, 8, 14, 15, 17

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OHIO

Technology Resource Center,
Enabling People with Disabilities
301 Valley Street
Dayton, OH 45404-1840
Phone: (513) 222-5222
Fax: (513) 222-2101
AppleLink: TRCD 1, 2, 3, 4, 5, 6,
8, 9, 10, 11, 12, 13, 14, 15, 16, 17

OREGON

**Oregon Outback Technology
Access Center**
P.O. Box 2916
La Grande, OR 97850
Phone: (503) 962-7258
AppleLink: OUTBACK
1, 2, 4, 5, 8, 10, 11, 12, 14, 15, 16

RHODE ISLAND

TechACCESS of Rhode Island
300 Richmond Street
Providence, RI 02903-4222
Phone: (401) 273-1990 or 273-
1991 TDD
Fax: (401) 831-1131
AppleLink: RHODE ISLAND
1, 2, 5, 8, 9, 12, 15, 16, 17, *Federal
Technology Act Center for Rhode
Island*

TENNESSEE

**East Tennessee Special
Technology Access Center, Inc.**
3525 Emory Road, N.W.
Powell, TN 37849
Phone: (615) 947-2191
Fax: (615) 947-2194
AppleLink: EASTTN
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14,
15, 16, 17

Technology Access Center of Middle Tennessee

Fountain Square, Suite 126
2222 Metro Center Blvd.
Nashville, TN 37228
Phone: (615) 248-6733
(800) 368-4651
Fax: (615) 259-2536
AppleLink: TAC
1, 2, 3, 4, 5, 8, 9, 12, 14, 15, 16, 17

West Tennessee Special Technology Resource Center

Lambuth University, Carney
Johnston Hall
401 Maple Street
P.O. Box 3683
Jackson, TN 38303-3683
Phone: (901) 424-9089
Fax: (901) 424-9090
AppleLink: WESTTN
1, 2, 3, 4, 5, 8, 9, 10, 11, 12, 13, 14, 15,
16, 17

TEXAS

SHIP Resource Center
University United Methodist
Church
5084 DeZavala Road
San Antonio, TX 78249
Phone: (210) 822-0995
Fax: (210) 696-7723
AppleLink: SHIP
1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15,
16, 17

UTAH

**Computer Center for Citizens
with Disabilities**
c/o Horizon Elementary School
5180 S. 700 West, Room 22
Murray, UT 84123
Phone: (801) 266-0600
Fax: (801) 266-0609
AppleLink: CCCD
1, 2, 4, 8, 12, 14, 17, *serves statewide
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evaluation teams*

VIRGIN ISLANDS

**Virgin Islands Resource Center
for the Disabled, Inc.**
P.O. Box 1825
St. Thomas, VI 00803
Phone: (809) 777-ABLE (2253)
Fax: (809) 774-5816
AppleLink: VIRGIN ISLDS
1, 5, 7, 15, 16

VIRGINIA

**Tidewater Center for
Technology Access**
Special Education Annex
273 N. Witchduck Road
Virginia Beach, VA 23462-6507
Phone: (804) 473-5136
Fax: (804) 473-5659
AppleLink: TCTA
1, 2, 3, 4, 5, 8, 9, 10, 11, 12, 14, 15, 16, 17

WASHINGTON

**Washington Technology Access
Center**
8705 232nd Place, S.W.
Edmonds, WA 98026
Phone: (206) 637-9848
Fax: (206) 776-3663
AppleLink: WTA
InternetLink: WTA @
AppleLink: Apple COM
1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15,
16, 17, *international newspaper,
license agreements with corpora-
tions and schools, two internation-
al conferences: Spring, April,
1994—Pacific Northwest
Technological Conference for
Special Needs: Virtual
Reality/Virtual Freedom confer-
ence, consults to corporations
and school districts*

WEST VIRGINIA

Project G.L.U.E.
c/o Children's Therapy Clinic
2345 Chesterfield Avenue
Charleston, WV 25304
Phone: (304) 342-6501
AppleLink: GLUE
Program information unavailable



Miriam uses an Apple Macintosh computer system with large print software.

An ATA Success Story

Eleven-year-old Miriam lives in a rural North Carolina county. Over a two-year period, she underwent five surgeries to remove a brain tumor. As a result, she now has visual impairments, poor fine motor coordination and instability when walking.

Miriam began receiving her schooling at home while waiting for her medical condition to improve enough for her to return to her regular fifth-grade classroom. Miriam's visual and fine motor impairments, however, prevented her from using paper and pencil to complete assignments as she had in the past. As Miriam's frustration increased daily, the home teacher suggested that her mother contact the Carolina Computer Access Center, an ATA center in Charlotte, NC.

After assessing Miriam's strengths and needs, Carolina Computer Access Center staff had a number of recommendations. Miriam would need to have a computer at home, and one should also be available in the classroom when she returned to school. They suggested a computer with large-print software for math and writing. A keyboard with large letters and numbers would be necessary. They also advised the use of "talking" software.

Since the family's insurance benefits would not cover all the costs of the recommended home computer system, the Center encouraged the family to look for other funding sources. Miriam's father found out that he could order a computer at a discounted cost through his company, and the family's church raised the necessary funds to purchase an Apple Macintosh LC II with an Echo speech synthesizer, printer and several recommended software programs. The special education administrator in Miriam's school district contacted the Center and ordered the same recommended computer equipment and software for Miriam's classroom. On the advice of the Center, Miriam's doctor also approved the purchase of a closed circuit television that would magnify printed materials so that Miriam could read the same books as her classmates at school.

Miriam is now back in the regular classroom for half days. Thanks to the use of assistive technology, she is able to learn alongside her peers and keep up with all classroom assignments.

Technology Use at Home

by Adele Schwartz



Twelve-year-old Heather is visually impaired. At home, she does her homework using a Macintosh LC computer with talking word processing software and enlarged screen text. She carries a portable Macintosh PowerBook, also equipped with the talking word processor "Write:OutLoud," to and from school in a backpack. (Photo courtesy of Don Johnston, Inc.)



Nine-year-old Dominic uses a portable augmentative communication device. (Photo courtesy of the Boston Public Schools Special Education Technology Center.)

If you have tried to obtain technology to help your child, you may have been frustrated by the lack of adequate assistance and information. You may have needed to learn about computer hardware and software or assistive devices. Even if already technologically competent, you may have felt the need for on-going consultation with someone with more expertise about your child's technology-related academic, social, vocational, sensory or physical needs. You may have been confused or overwhelmed by negotiating funding entitlement. You may have invested money in technology that turned out to be incompatible with what was used in school or inappropriate for your child. You may have found that your child's teachers or therapists know less than they should about new technologies, or that they are not communicating with you about how technology is being used in school and how your family can support those efforts at home. You may have found it difficult to find technology resource centers outside of the schools.

If any of these experiences sound familiar, you are not alone. Even parents who have succeeded in providing computer and assistive technologies for their children's use report similar frustrations and experiences.

1988: Public Law 100-407

P.L. 100-407, the "Technology-Related Assistance for Individuals with Disabilities Act of 1988," was enacted to stimulate the use of assistive technology. Technology assistance centers were established with funding from state education departments, foundations and the federal government through this legislation. These centers, along with the Alliance for Technology Access (ATA) centers throughout the country, became valuable resources to many parents. Still, the technology needs of many children remained unmet because of inadequate access to quality assistance, costs involved or insufficient parental knowledge of children's entitlements.

1990: Public Law 101-476

In recognition that many children with disabilities still did not have access to the technology from which they could benefit, the "1990 Individuals with Disabilities Education Act (IDEA)," P.L. 101-476, included mandates to correct these inequities. This new law required that school districts take responsibility for identifying children's technology needs; securing, maintaining and repairing needed devices, and providing the child with services to insure appropriate technology use. According to this law, a child's Individualized Educational Plan (I.E.P.) must include the nature of needed technology support and the kind and amount of support services to be provided in school. Yet, some state education departments have not yet issued reg-

ulations for their school districts to enforce the IDEA, and many schools are not in compliance with the Federal requirements.

Parental Survey Results

Past history shows that schools will respond when parents are empowered with enough information about their children's rights to make appropriate demands. Recently, I conducted a national study of the experiences of families who have computer and/or assistive technologies available for home use. The parents in this study were all on the mailing lists of eleven centers affiliated with the Alliance for Technology Access (ATA). Two hundred thirty-four parents responded to a ten-page survey. Parents were asked about sources of information and continuing support, their children's use of technology at home and school, and areas of ongoing need.

This article will review the experiences reported by parents who answered the survey and will provide some suggestions to help build or increase home-school collaboration concerning technology.

• How have parents secured assistance?

Many parents of children with disabilities report that they buy computers and academic software primarily for the educational benefit of their children, particularly for enrichment or remedial work. They also buy computer games, video games and hand-held games to provide oft-needed additional recreation choices.

Parents have had to be resourceful to get these technologies for home use. Some became computer literate on

their own, or at work; some found technological information in computer magazines or *Exceptional Parent*. Some spoke with other parents, contacted manufacturers or vendors directly, or sought advice from teachers, therapists and other professionals.

Parents reported getting information from schools and other sources in addition to the ATA center. Even with multiple sources, some parents said that they still needed additional help. As their children became more sophisticated users of the technology, they required additional assistance from parents.

The greatest areas of need cited by families already using technology at home were for assistance with financial aid sources (55%), information about the design of the home computer environment (53%), ongoing consultation with an expert (46%), and connection to other families in similar circumstances (45%). Services rated most useful were demonstrations on how to assist their children (83%), information about purchase or loan of software (81%) and hardware (71%) for home trial, the availability of an expert consultant (78%), technological literacy training for parents (76%) and financial resource information (69%).

• How much is technology used at home?

Although parents reported somewhat limited use of technology at home, parental enthusiasm about outcomes of that use was high. Among school-age children and youth, academic subject software was available in 50% of the homes. Among these families, however, 27% of the children did not use the available academic subject software at all, while 59% used it, but only for 1-3 hours per week.

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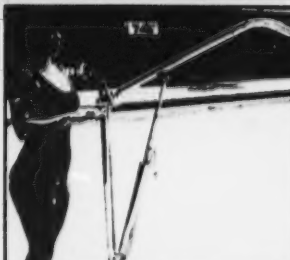


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Word processing software was available in 65% of the homes, but was not used at all by 38% of the children; 50% of the children used word processing software for 1-3 hours weekly. Graphic design, database, programming and informational access software were available in far fewer households, and used much less than academic and word processing software in homes where they were available.

Assistive devices were used with greater frequency. Augmentative communication devices, assistive devices for children with visual disabilities and devices used to control the physical environment were used from 1-10 hours per week by 73% of those who had them. Some devices were not in use because of the need for repair, some families lacked adequate knowledge of how to use the devices they had, and some children had "outgrown" the usefulness of their assistive devices.

Recreational technology was used by most families responding to the survey. Of those children aged 6-21 who owned computer games, 66% used them for 1-3 hours per week. Video games were used by 46% and hand-held games by 48% for the same 1-3 hours per week.

More research should be done to determine reasons for the relatively limited use of technology at home. Based on parent comments written on the surveys, however, many deterrents to more extended technology use have to do with lack of communication or collaboration between home and school regarding technology use.

Many parents report that despite the inclusion of technology services on an I.E.P., such services are sometimes reduced or not provided at all. Teachers assign little or no homework requiring technology use at home. Some educators seem unable to assist parents in matters related to tech-

nology, and those staff members with expertise seem over-extended and unable to offer parents much assistance. School personnel rarely know about, or refer parents to, outside technology resource centers.

Home-school collaboration

If the results of this study, conducted in 10 states, including urban, suburban and rural locales, is indicative of the status of IDEA implementation in other parts of the country, then IDEA mandates are not yet being met in most school districts, and technology is not yet being used to its full potential in school or at home.

If IDEA is to fulfill its promise, parents need to know its mandates, make children's schools aware of this parental knowledge and begin to demand that the law's requirements be met. The first priority is to make sure all children gain access in school to the kind(s) of technology that are appropriate to their needs. If obtaining the necessary technology requires application to federal, state or local agencies, parents may need to seek help from school staff to expedite the paperwork.

When parents also want the technology to be available at home, some schools have helped reduce costs by arranging payment plans or group discounts. Others have worked with local philanthropic organizations to assist families with limited means. Parents may need to join together to help some underfunded and overburdened schools to meet the law's mandates. Parents may decide to share computer software, arrange for sales of used devices or software, or establish "hand-me-down" exchanges as children outgrow computer programs, assistive devices or other hardware.

Teachers and therapists need to include technology devices and services on I.E.P.s and parents need to monitor how well goals are met. Parents can make teachers and therapists aware of any technology available at home, and, where appropriate, ask them to consider assigning homework that requires the use of that technology.

Parents may also want to look for demonstrations of how they or willing siblings can assist a child at home. In this study, parents and siblings played an important role in promoting home technology use by the child with a disability. School districts can provide these demonstrations or refer parents to outside agencies that can help. Parents may need to ask to be kept informed about technology instruction and use in school, and request regular progress reports.

Parents with some free time and technical expertise can also be very useful in helping school staff to develop technology programs. Parent groups, like computer "user groups," can be formed to help parents exchange ideas and learn new ways to use the technology more effectively and efficiently. ■

Adele Schwartz, Ed.D., is Director of Special Services at the Hunter College School of Social Work, City University of New York. Before coming to Hunter, she worked as a special education teacher in the New York Public Schools, and also administered programs of advocacy for, and empowerment of, parents of children with disabilities. She has taught several courses in Hunter's Department of Special Education, including a course for teachers on working more effectively with families of children with disabilities.

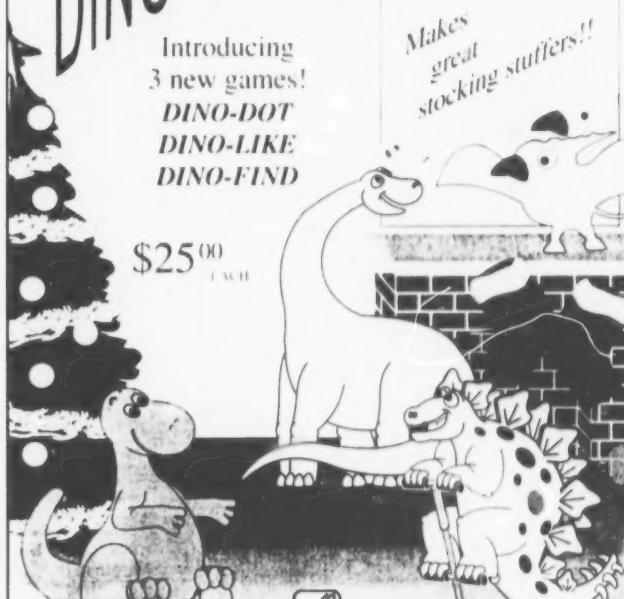
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Reflections on a Birthday

by Alysoun Reichard

Heidi turned three last December. No child ever had a better birthday. She had been thoroughly exposed to the rituals of birthdays through books and videos, and her expectations were high. When she got up in the morning, I wished her a happy birthday and told her that now she was the birthday girl! Her answer was to the point: "Where's my cake?"

Heidi's therapist came by that morning and brought her a present. I am so jealous of my daughter's ability to gush. Very dramatically, she exclaimed, "Oh! A present? For me?" When she opened it and discovered a Big Bird view-master, she was thrilled.

Heidi's preschool class at the Southington YMCA celebrated the day with cupcakes she had brought. She got to wear a special crown while the children sang "Happy Birthday" to her.

Heidi was in her glory when I picked her up after school, but there was more to come. We had invited eight of Heidi's friends to a party at Burger King, and she had helped me with the invitation list.

Burger King has one of those indoor play areas with a slide that ends in a sea of colored balls. It wasn't exactly designed to be accessible, but we'd tried it out ahead of time and determined that we could get Heidi into the balls, and then back out again. Heidi had a great time playing in the balls while the other children frolicked. Again, she did a great job of gushing as she opened her presents, and she smiled broadly as the children sang to her.

Exhausted by the excitement and fun of the day, Heidi fell asleep in the car on the way home from her party. She woke up from her nap to even more surprises. A close friend of ours had made her a Big Bird cake. And she got to open more presents—this time from her family.

After all of the excitement, Heidi had a little trouble falling asleep that night. So did I. As I was getting ready for bed, I thought about what a wonderful day it had been, and about the special joy of experiencing a child's birthday. Then another thought occurred to me and I began to cry. Heidi had enjoyed her birthday every bit as much as any normal child ever has and, at least for one day, spina bifida was not important and did not get in the way.

I'm always telling people that Heidi is more like other children than different from them. But sometimes, when I get caught up in doctor's appointments and therapy visits, I lose a little perspective. That night, my tears were tears of relief and recognition. At that moment everything was brought into focus for me. I felt as if I had gotten a glimpse into Heidi's future. Suddenly I could imagine her as a teenager with friends, and later as a happy, well-adjusted and productive adult. And after all, isn't that what we all wish for our children? ■

Alysoun Reichard lives in Kettering, Ohio, with her husband, Dave, and daughter, Heidi. She writes frequently about issues related to spina bifida.

Above: Heidi celebrates her third birthday.

FATHERS' VOICES

The Silent Ringmaster

by Robert Greenwald



Robert Greenwald with David, age five.

Fathers' Voices is a regular feature of *Exceptional Parent* magazine. This column, coordinated by James May, Project Director of the National Fathers' Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers' Network, The Merrywood School, 16120 N.E. Eighth Street, Bellevue, WA 98008, (206) 747-4004 or (206) 282-1334. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with the National Center for Family-Centered Care, a program of the Association for the Care of Children's Health, Bethesda, MD.

I awoken from a dream
of fathers and sons
to the sound of my own blood
stirring in another room.
Crossing the moonlight,
I open your door,
but you have quickly fallen
back asleep. Motionless.
Your fastened eyelids
hold off the light.
What lies behind them
twists the day into memory?...
perception?... nothing?
Does darkness, for you,
burn brighter than day?

Your room is like a circus tent,
filled with the things
your mother has done to brighten it:
on your dresser
a night-light clown sells balloons
that glow with electric color;
the unicycle hanging
from a ceiling corner
sends another clown wheeling
across some invisible tightrope;
up the wall a hot air balloon

lifts its furry passengers
beneath a sculptured rainbow.
And on the shelf above your bed
a menagerie of stuffed animals
huddles in stunned silence—
the lion, the elephant,
bulldog and bears,
some with music in their bellies.
They hold their quiet vigil
over you, the keeper, the
silent ringmaster.

What they glimpse with their plastic
eyes blazes back at me
like the echo of a question whispered
over and over in this same still room:

"What thoughts, what dreams
can flare in the head
where so much brain is useless?"
What wonder for this child
who cannot imagine a circus?

Oh, my son, what I would give
to move behind the blueness
of your eyes,
to assemble the fragments of sight and
sound to make the animals come alive.
I would rise up like a ringmaster
and crack the whip
that sends the lion roaring
through rings of fire,
or the elephant standing on
one hind leg,
or bears—many bears—
dancing in an awkward circle.
All sound! All color! All motion
coming together in mid-brain
with whip-snapping clarity!

And the painted clown would turn
his somersaults and handstands,
baggy legs kicking in the air.
The fisted bulldog
would strut on two feet.
The balloon would rise higher,
and higher still,

taking on a rainbow of colors,
while another clown scrambles
up the fearsome pole
toward the high wire
thrumping in your head.

And you, my child, would be amazed
by this greatest show on earth;
your gaze becoming sharpened
and meaningful,
enthralled by the shapes appearing,
the air spinning into pure light,
this instant flickering of colors
you did not know existed.

Every nerve vaulting!
Every synapse joining!
Every pulsing message reaching

the failed brain!
Your palsied hands coming suddenly
together in applause,
understanding, for a moment,
the mystery of symmetry,
poise and power
here, beneath the big top:
where the ringmaster's heart stands

up kingly inside him;
where a child's wonder
is suspended in awesome balance,
like the spoked wheel
flashing in the wire,
like the elephant on one leg,
like the whole circus
singing and weeping in our heads.

This poem is part of a collection of poetry Robert Greenwald has written about his son, David. He has recently completed a book consisting of these poems and the story of David's life. He hopes to see it published within the next year.

David was born in 1979 with a congenital heart disease. At six weeks of age, he went into heart and respiratory failure, and suffered severe brain damage from lack of oxygen. He died in 1987 of pneumonia and congestive heart failure.

Mr. Greenwald is a produce manager/merchandiser and freelance copywriter for an advertising and public relations firm. His wife, Barbara, is a consultant for the Family Information Network, a grant-funded organization assisting families of special children. They live in Munroe Falls, Ohio, with Katie, age 13; Steven, age 9; and two foster children with disabilities, ages 4 and 11 (names withheld due to confidentiality requirements).

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Parent to Parent National Survey

Parent to Parent (P-P) programs provide emotional and informational support to parents of children who have special needs. To provide this support, trained and experienced "veteran" parents are carefully matched in one-to-one relationships with parents who are newly referred to the program. The veteran parent has shared the experience of a disability in the family and can provide the unique kind of support that can only come from another parent who has "been there." In the fall of 1988, the Beach Center on Families and Disability at the University of Kansas initiated a national survey of Parent to Parent programs.

Why we did this research

While Parent to Parent programs have been providing information and emotional support to parents for over twenty years, little had been written about these programs. No one knew for sure how many programs there were, how they were structured administratively, and exactly what kinds of services were being provided. No one had gathered information from program coordinators or parents about their participation in P-P programs. As a result, it was hard for many families to find a P-P program in their community, and parents and service providers who were interested in starting a program had little information to guide them.

What we learned

P-P programs have grown from one—the Pilot Parents Program at the Greater Omaha (Nebraska) Association for Retarded Citizens, founded in the early 1970s—to over 350 active programs. We estimate that over 20,000 parents are currently participating in a P-P program.

P-P programs exist in every region of the country. Some are small pro-

grams that serve just a few parents; others serve several hundred families. An "average" program provides support to between 13 and 25 referred parents. While a few have budgets of over \$100,000, the majority have annual budgets of less than \$5000. Fewer than half have a paid coordinator; all veteran parents are unpaid.

All programs provide emotional and informational support to families. Most programs serve families whose children have a range of disabilities. Of the families participating as referred parents, 85% have a child with special needs who is younger than 12, although an increasing number of programs are now matching families who have adolescents or young adults. With the growing emphasis on early intervention services for infants and toddlers, more and more families are being connected with programs shortly after the birth of a child who has a disability.

Referrals come from different sources, 88% being made by medical personnel. Most matches are made based upon similarity of the child's disability and family issues. Once the match is made, contacts between the referred parent and the veteran parent may take place over a very brief period of time, or may continue and develop into a lifelong friendship.

The one-to-one matched relationship provides new parents with someone who can listen and, whenever possible, offer information about the

disability—the two support services ranked as most important by referred parents. Other program supports may include information about community resources, information about living with and caring for the family member with a disability, referrals to other agencies, problem-solving support, group activities for support and fun, and advocacy training.

Sixteen states have established statewide P-P networks in addition to local programs. Statewide networks often provide training and assistance to local programs and allow parents from different areas to be matched when a local match isn't available.

More research in the works

While parents know the value of one-to-one Parent to Parent support, there has been no research data to validate parent testimonials. P-P programs are now requesting research to determine the effectiveness of P-P supports. Such research is expected to enhance program credibility and fundability.

In response to these requests, the Beach Center is currently directing two studies, each involving several hundred parents participating in P-P programs. The first is a three-year study to determine the impact of P-P support on referred parents. The second is a five-year study that will examine the impact of P-P support *over time* on referred parents, veteran parents, and on the child with a disability. ■

The Beach Center on Families and Disabilities is a federally funded research and training center dedicated to improving supports for families who have a member with a disability. The center has published additional information on the results of the national survey of P-P programs. For reprints of these articles and additional information about the Center or P-P programs, contact: The Beach Center on Families and Disabilities, The University of Kansas, 3111 Haworth Hall, Lawrence Kansas 66045, (913) 864-7600.

NETWORKING

Information from The National Parent Network on Disabilities

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CONTENTS:

Annual NPND Legislative Conference	43
NPND's Position on Inclusion	44
NPND Position on School Reform	45
Health Care Reform Initiative Relaunched!	45
Inclusion in Education: A Choice for Your Child	46

Parent Leaders Develop Legislative Agenda



Judy Heumann & Diane Cuthbertson with some attendees of the Legislative Working Conference

Annual NPND Legislative Conference

Diana Cuthbertson

The first Annual Legislative Conference of the National Parent Network on Disabilities was held on September 18 and 19th, 1993, in Washington, DC. The weekend began with sharing ideas from around the states (with 25 states represented), as well as hearing from and having dialogues with key national leaders. Then on September 20th, members of the Network visited with their legislators and staff members knowledgeable of disability rights issues. Our weekend began with confirming our busy agenda:

3. To develop a position statement regarding supported inclusion education.
4. To prepare for meetings with members of the Hill.
5. To develop strategies for dissemination of information to NPND members and to elicit their input and support.

While some of the goals, as they are fully implemented, will become part of a three year plan for the Network, we were successful in accomplishing all of the immediate goals over the busy three days.

The NPND position paper on Education Reform, published in a previous issue of *Exceptional Parent*, was expanded to confront recent "reform efforts and proposals at the federal, state and local levels which have often focused on removing the essential protections of IDEA or ignored the existence of children with disabling conditions and their parents. In the past major federal initiatives involving school-age children, many have not included specific provisions for students with disabilities. The "education report card" by the National Governors Association to assess the nation's progress toward the six national edu-

GOALS FOR LEGISLATIVE MEETING

1. To formulate NPND position statements or guiding principles regarding pending federal legislation including Reauthorization of IDEA, Family Support and Health Care Reform.
2. To obtain an update from Washington and give input to emerging national policies and legislation related to disability rights.

INFORMATIONAL FORUM

cation goals briefly referred to students with disabilities but omitted any identifiable measures or indicators that specifically reflect the accomplishments of students who receive special education and related services. Some state reform efforts have eliminated special education offices and positions and have attempted to repeal specific state protections for children with disabilities and their parents. State and local education officials across the country have called for the elimination of separate funding streams for special education services.

The NPND strongly believes that these actions are based at least in part on the exclusion of parents of children with disabilities from school reform planning and implementation efforts. Parents of children with disabilities must participate fully in deciding: (1) what we want students to know and be able to do; (2) what schools must provide in order to help children reach those goals; (3) the means by which schools will provide the necessary opportunities to learn; and (4) how we

will assess whether schools follow through on their obligations to all children. "We will not accept exclusion from or mere token participation in school reform."

Several national experts were able to attend the meeting and share their priorities as the new administration is taking shape. Assistant Secretary Judith Heumann reported on recent testimony she has gathered through meetings with grassroot family members around the country. The Network expressed our concerns to her about the critical need for enhanced federal monitoring and strict enforcement of federal laws regarding special education. Robert Silverstein, Majority Staff Director of the Senate Disability Policy Sub-Committee, engaged in a discussion of several key pieces of pending legislation. He reflected on the progress achieved under P.L. 94-142 and its amendments, but as we look ahead to its reauthorization during the coming year, we maintain all of the due process protections for children and parents.

Disability rights advocates including Celene McQuarter from TASH and Alan Bergman from United Cerebral Palsy gave national updates from their organizations. Alan also focused our discussion on Health Care Reform and people with disabilities. **It is important for every parent to learn as much as you can about the new plans and inform state Senators and Congressmen about how the proposed health care reform will effect your family. Contact Family Voices, a new family coalition focused on health care reform, if you need more information (505) 867-3159.**

If you want complete copies of any of the NPND Position Papers to assist in advocacy efforts at your local district or state level, please contact NPND (703) 684-6763. Plans were being formulated as we closed the first Annual Legislative Conference for next year's meeting. We will inform you as soon as we have selected a date so you can start your fund raising activities and join us next year!

NPND's Position on Inclusion

Inclusion is not a place, it's an attitude, an attitude that fully accepts all children in their schools and communities; that welcomes full participation of parents of children with disabilities in schools and school reform efforts; that fully includes adults with disabilities in all aspects of life and areas of civic responsibility. It is an inalienable right, not a privilege. Thus, a supported inclusive education option must be available to all children regardless of the type or severity of their disability.

The goal of education must be to maximize the ability of children to learn and function at their full potential, and to grow into adults who can participate fully in our society. Toward that end, the National Parent Network on Disabilities reiterates our support for the Individuals with Disabilities Education Act and its implementing regulations, which establish a goal of providing full educational opportunities to all children with disabilities, including to the maximum extent appropriate the provision of special services to enable children

to participate in general education programs. As mandated by IDEA, children with disabilities must be educated with their non-disabled peers and must not be removed or segregated unless their needs cannot be met in that environment even with the provision of all necessary supports and services. This is vital both for children with and without disabilities. Encouraging all children to accept and appreciate diversity not only better prepares all students for life, but also fosters a society undivided by race, class, language or disability.

NPND believes that fully supported inclusive education is best for most children most of the time. However, we recognize that some children require other options based on their own individualized education needs as determined by a team including their parents and themselves if appropriate. Despite the clear language of IDEA, some states, districts and schools refuse to provide fully supported inclusive education options for children. Services have been based not on student needs but merely on administrative convenience. The NPND urges more effective monitoring and

enforcement by the U.S. Department of Education to remove barriers to fully supported inclusive education options based on the configuration of the service delivery system or funding mechanisms, the availability of educational or related services, the availability of space, curriculum content, appropriately trained and qualified staff and administrators, or the method of service delivery.

Acceptance and inclusion lead to empowerment and independence. Our children have a right to expect nothing less.

Networking is information from the National Parent Network on Disabilities. The Network is a membership organization open to all agencies, organizations, parent centers, parent groups, professionals, and all individuals concerned with the quality of life for people with disabilities.

Patricia M. Smith Executive Director
Connie K. Hawkins Editor

NPND Position on School Reform

In order to assure that every child in the country realizes his/her potential and achieves the life role of his/her dreams, we recognize the urgent need to reform the public education system in this country. We are ready to commit our full energy, resources, expertise and spirit to strive for more positive educational outcomes for *all* children.

As parents of children who participate in both regular and special education programs, we are in the unique position of experiencing and valuing both. Based on our eighteen years of experience with the law now known as IDEA, we are committed to the belief that the protections embodied in that law are critical to assuring that *all* children receive a free, appropriate public education. We, therefore, urge that the basic tenets of IDEA be viewed as a role model for the education of *all* children. Minimally, we affirm our commitment to IDEA, oppose any revisions to it, and urge that its basic tenets be applied to the reform of regular education.

Instead, reform efforts and proposals at the federal, state and local levels have often focused on removing the essential protections of IDEA or ignoring the existence of children with disabling conditions and their parents. In the past major federal initiatives

involving school-age children, six have not included specific provisions of students with disabilities. The "education report card" by the National Governors Association to assess the nation's progress toward the six national education goals briefly referred to students with disabilities but omitted any identifiable measures or indicators that specifically reflect the accomplishments of students who receive special education offices and positions and have attempted to repeal specific state protections for children with disabilities and their parents. State and local education officials across the country have called for the elimination of separate funding streams for special education services.

The NPND strongly believes that these actions are based at least in part on the exclusion of parents of children with disabling conditions from school reform planning and implementation efforts. Parents of children with disabilities must participate fully in deciding: (1) what we want students to know and be able to do; (2) what schools must provide in order to help children reach those goals; (3) the means by which schools will provide the necessary opportunities to learn; and (4) how we will assess whether schools follow through on their obligations to all children. **We will not accept exclusion from or mere token participation in school reform.**

Health Care Reform Initiative Relaunched!

By Larry Searcy

On October 27th, President Clinton formally transmitted his 1300 plus page Health Security Act to Congress. The plan has been refined since September when the first version was informally released. At least five other health reform plans are being considered by the Congress.

With the President's plan, as it now exists, comes good news and bad news. The good news is that universal coverage appears to be the cornerstone of the plan and the Administration does not seem likely to deal it away. If so "pre-existing conditions" will be a thing of the past. The Administration also seems secure with the notion that one's ability to get good health care should not revolve around one's place of employment. Hence, family members who may need to work part time or not at all would be able to avail themselves of at least the proposed package of national health care benefits.

However, the plan, as now written, takes a very medically traditional view of long term care, physical rehabilitation and other similar services. It requires, for instance, that to continue with physical therapy, a person must demonstrate improvement over time and a cap is placed on the amount of

Continued on page 46

NPND Invites You to Join

Mission:

The National Parent Network on Disabilities (NPND) was established to provide a presence and national voice for parents of children, youth, and adults with special needs. NPND shares information and resources in order to promote and support the power of parents and resources to influence and affect policy issues concerning the needs of people with disabilities and their families.

Membership Fees

Parent Coalition - Voting (Call NPND for details)	\$ Sliding Scale
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Please return this form with your check made payable to: The National Parent Network on Disabilities, 1600 Prince Street, Suite 115, Alexandria, Virginia 22314, (703) 684-6763.

INFORMATIONAL FORUM

Inclusion in Education: A Choice for Your Child

By Bonnie Schoultz

The Advocacy Board of the Center on Human Policy has developed a flyer for parents titled "Inclusion in Education: A Choice for Your Child." The flyer points out that "Inclusion is possible for ALL students, including YOUR child," and that "The key to success for inclusion is to build the services and supports necessary to insure a good program." It was developed to encourage parents to advocate for inclusive education for all children, and to inform those whose children are in self-contained classrooms that they do have a choice.

This flyer can be used to inform parents and educators who are unsure about inclusion, and can be used to inform others by advocates for inclusion. The Advocacy Board is preparing to distribute the statement locally, but encourages anyone interested to duplicate and disseminate the flyer within their own district or state. The flyer is free and can be obtained by writing to Rachael Zubal, Center on Human Policy, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-2340.

The flyer provides 13 statements under a heading, "Inclusion means:" including the following examples.

Inclusion means:

- * Providing all students enhanced opportunities to learn from each other's contributions.
- * Supporting regular teachers and administrators (e.g., by providing time, training, teamwork, resources, and strategies).
- * Involving students with disabilities in age-appropriate academic classes and extracurricular activities, including art, music, gym, field trips, assemblies, and graduation exercises.
- * Teaching all children to understand and accept human differences.
- * Taking parents' concerns seriously.

The flyer gives nine statements of what inclusion does not mean. Following are some of these statements.

Inclusion does not mean:

- * It does not mean "dumping" students with disabilities into regular programs without preparation or support.
- * It does not mean providing special education services in separate or isolated places.
- * It does not mean ignoring children's individual needs.
- * It does not mean placing unreasonable demands on teachers and administrators.
- * It does not mean requiring that stu-

dents be "ready" and "earn" their way into regular classrooms based on cognitive or social skills.

A packet of resources on inclusive education (articles, sample case studies, and a bibliography) is available for the prepaid fee of \$7.20, and may be ordered from the address listed above.

This was prepared by the Research and Training Center on Community Integration with support from the National Institute on Disability and Rehabilitation Research. No endorsement by the U.S. Department of Education of the opinions expressed should be inferred. For more information on this topic, write to the author at the Center on Human Policy, 200 Huntington Hall, Syracuse, NY 13244-2340.

For a list of references and select resources, contact NPND, 1600 PRINCE ST., #115, ALEXANDRIA, VA 22314.

Health Care Reform Initiative Relaunched!

(continued from page 45)

service a person may utilize. Additionally, the Administration has agreed to limit the total amount of funding support for subsidies to economically disadvantaged Americans and to curb the potential economic impact of the plan on small businesses. Rumors abound that all aspects of the bill may yet change. Disability advocates are not optimistic that the needs of people with disabilities will be addressed in the Administrations' legislative package.

We would greatly appreciate any input you may have and urge you to share your health care needs with the Administration by writing Ms. Carol Rasco, Domestic Policy Council, The White House, 1600 Pennsylvania Ave., NW, Washington, DC 20500. If you could send NPND a copy of anything you forward to the White House it would be greatly appreciated. Your communication with the White House can take any form that best tells your family's story.

NPND will keep its membership informed via our fax tree and other means of rapid communication as things heat up. It's important to note that the debate is now which plan is best. The need for reform is no longer an issue.

★ ★ ★ Announcing ★ ★ ★ The NPND 1994 Annual Meeting

JANUARY 22, 1994

at

THE CRYSTAL CITY MARRIOTT

Tentative Agenda Includes

- Early Bird Working Sessions on:

(9:00 AM - 12:00 Noon)

* Education Reform

* Health Reform

* Family Support

- NPND Business Meeting

(12:00 Noon - 4:00 PM)

Silent Auction and Joint Receptions with TAPP and NECTAS

Sunday Evening, January 23, 1994

All Children Belong

The National Parent Network on Disabilities (NPND) has received a \$600,000, three-year grant from the Dewitt Wallace-Reader's Digest Fund. The grant was made as part of the Fund's School/Family Partnership Initiative, which is designed to increase families' involvement in the education of their children.

The NPND will use the money to work with the Statewide Parent Advocacy Network of New Jersey to implement a project known as *All Children Belong* (ACB), to help parents promote inclusion of children with disabilities. ACB is an awareness and training program designed to help communities support the learning and participation of each student, especially children with disabilities. The program focuses on opening doors for students and creating more options for participation in school, work and community activities. It provides a framework for problem-solving on various levels—that of the individual student, school, district and

state—to ensure that all necessary supports will be in place.

ACB was developed in New Jersey during a four-month planning period also funded by the DeWitt-Wallace Reader's Digest Fund. During this development period, the NPND created a model for local Community Inclusion Action Teams that will support inclusion of children with disabilities in regular classrooms.

During its first year of operation, ACB activities will take place in 20 states in the South and Midwest. During its second year, the ACB model will be expanded to 17 sites in the West and Northeast. In 1994, *Exceptional Parent* will be reporting regularly on this exciting project.

For further information about *All Children Belong*, contact Patty McGill Smith or Larry Searcy at 115 Prince Street, Suite 115, Alexandria, VA 22314, (703) 684-6763, FAX (703) 548-6191, or contact Diana Cuthbertson at 516 North Avenue East, Westfield, NJ 07090, (904) 654-7726, FAX (908) 654-7880.

Tax on customized vehicles repealed

In 1992, Congress imposed a ten percent luxury tax on any vehicle purchased after January 1, 1991, and costing more than \$30,000. The intended targets of this tax were high-priced cars, yachts and jets. However, vehicles converted or adapted for use by individuals with disabilities were often taxed also, because the addition of customized equipment raised the retail price of such vehicles to more than the \$30,000 limit.

Greg Anesi, founder and president of Independent Mobility Systems, a van conversion company, initiated an effort to repeal the tax on specially-equipped vehicles for people with disabilities. With the help of U.S. Sen. Pete Dominici and U.S. Rep. Bill Richardson, both of New Mexico, legislation to repeal the tax was introduced in the Senate and the House. The repeal was passed in

August and covers passenger vehicles sold since the beginning of 1991, when the tax first went into effect. Since the tax repeal is retroactive, the amount paid as tax can be refunded to the taxpayer.

The person who paid the tax directly to the Internal Revenue Service may claim a tax credit or refund by filing Form 848, *Claim for Refund and Request for Abatement*. Typically, the luxury excise tax would have been paid by the retailer and passed onto the purchaser as part of the purchase price. In such cases, the person who bought or leased the vehicle should contact the retailer for reimbursement of the tax paid. Once the vehicle's buyer or lessee has been reimbursed, the retailer can receive a refund or credit from the IRS by filing Form 848.

Report on Assistive Technology

Assistive technology (AT) helps three-fourths of the children with disabilities who use it to remain in regular classrooms, according to a new report by the National Council on Disability. According to the Council, technology has reduced school-related services required by students with special needs by forty-five percent. The report, *On the Financing of Assistive Technology Devices and Services for Individuals with Disabilities*, took a broad look at the current status of assistive technology legislation and made the following suggestions to Congress:

- A national classification system for AT devices should be developed. A central registry should disseminate AT information to parents of children with special needs.
- The National Institute on Disability and Rehabilitation Research should submit an annual status report on AT to Congress.
- State plans should be amended so that parents and children are notified of their right to request AT at the time a child is being evaluated for special education services.
- AT needs should be provided for in legislation such as the Social Security Act, the Maternal and Child Welfare block grant, Medicare and Medicaid.
- The Technology-Related Assistance Act should be re-authorized.
- The Tax Code should be amended to make AT available even when income adjustments are not itemized.
- National guidelines should be created for universal product design (e.g. lowered sidewalk curbs) to reflect modifications that can help everyone, not only individuals with disabilities.

For information about the report, contact the National Council on Disability, 800 Independence Ave., S.W., Suite 814, Washington, DC 20591, (202) 267-3846. Copies are available for \$13.75 from ERIC/CBIS, 7420 Fullerton Road, Suite 110, Springfield, VA 22153, 1-800-443-3742.

Hereditary Hearing Loss Research Registry

The National Research Registry for Hereditary Hearing Loss has been formed by the Boys Town Research Hospital in order to provide a national center to match families and individuals with researchers studying hereditary hearing loss. To register, or for more information, contact: Boys Town Research Register for Hereditary Hearing Loss, Boys Town National Research Hospital, (402) 498-6739 (V) or (402) 498-6631 (TDD).

TEF/VATER Support

The TEF VATER Support Network provides support and information to families and publishes a quarterly newsletter by and for families of children with Tracheoesophageal Fistula, Esophageal Atresia and VATER association. Contact: TEF/VATER Support Network, c/o Terri Burke, 15301 Grey Fox Road, Upper Marlboro, MD 20772.

Resources for Families of Children with Cardiac Anomalies

Congenital Heart Anomalies—Support, Education & Resources, Inc. (CHASER) is a nonprofit organization specializing in the needs of the cardiac child and family. CHASER offers parent-to-parent networking through a national database that matches families dealing with similar heart defects, surgeries, accompanying disorders, syndromes and other specific needs. The organization also acts as an information clearinghouse, offering resources to state and local assistance programs and family support groups. Quarterly educational newsletters contain articles of interest, professional profiles, and news of medical advancements in the treatment of congenital heart defects.

For more information, contact: CHASER, Inc., 2112 N. Wilkins Rd., Swanton, Ohio 43558, 419-825-5575.

Publications

- The *SSI Liaison Newsletter* is a free publication of the National Center for Policy Coordination in Maternal and Child Health. The newsletter is intended for those interested in resources for children with special health care needs, and serves as a forum for exchanging ideas and information on materials, policies and regulations related to the SSI Program for children. To receive this newsletter, contact: John Reiss, National Center for Policy Coordination, 5700 S.W. 34th St., Suite 323, Gainesville, FL 32608-5367, (904) 392-5904, Ext. 241.

Additional information on SSI is available through the *SSI Helping Kids Video*. The video is free and can be ordered from: MCH Clearing House, 8201 Greensboro Drive, Suite 600, McLean, VA 22102, (703) 821-8955, Ext. 251, Fax (703) 821-2098.

- *Fragile X Syndrome. A Handbook for Parents and Professionals*, published in 1993, provides the latest information on Fragile X including characteristics,

genetics and family impact. The cost is \$2.00. Contact: National Fragile X Foundation, 1441 York Street, Suite 215, Denver, CO 80206.

- Hot off the press is a reader-friendly book entitled *The Americans with Disabilities Act: A Guide for People with Disabilities, Their Families, and Advocates*. This 64-page book, also available on cassette, explains how the ADA prohibits discrimination against Americans with disabilities and how the ADA defines "an individual with a disability." Cost is \$8.00. Order from: PACER Center, 4826 Chicago Ave. S., Minneapolis, MN 55417-1098. Make checks payable to "PACER Center." Specify print or cassette.

- Another source of information on the ADA is a brochure entitled *The Americans with Disabilities Act: Questions and Answers*. It is free and is available in print and other formats from the Public Access Section, Civil Rights Division, U.S. Dept. of Justice, P.O. Box 66738, Washington, DC 20035-6738, (202) 514-0301.

- *Computer-Disability News* is a quarterly newsletter that provides



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For more information, please contact Vincent Strully, Jr., Executive Director.

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New England
Center for
Autism, Inc.**

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Just 20 miles from Boston.

information and news on assistive technology for people with disabilities. Send \$18 (U.S.) for a one-year subscription to: Communications, National Easter Seal Society, 70 East Lake St., Chicago, IL 60601-5907.

- **Inclusion News** is published by the Centre for Integrated Education & Community. A copy can be obtained by sending \$2 to: Inclusion Press, 21 Thome Crescent, Toronto, Ontario, CANADA M6H 2S5.

- **Air Carrier Access** is a free booklet that answers common questions about air travel. Contact: Eastern Paralyzed Veterans Association, 72-20 Astoria Boulevard, Jackson Heights, New York 11370, (800) 444-0120.

- **Yes You Can!** is a 36-page booklet to help young people with learning disabilities understand and help themselves. Send \$3.50 to: Communications, National Easter Seal Society, 70 East Lake Street, Chicago, IL, 60601-5907. A free publications catalogue is also available. ■

PRODUCT SHOWCASE



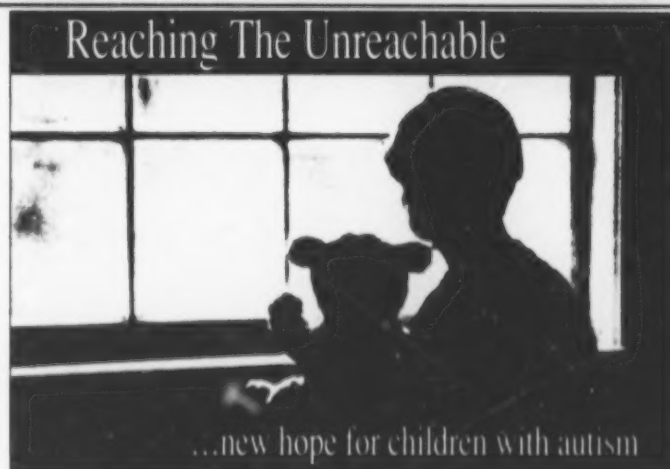
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Tax Options and Strategies for People with Disabilities

by Steven B. Mendelsohn, © 1993.
Published by Demos Publications, 386
Park Avenue South, New York, NY
10016. To order call 1-800-532-8663,
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Chapter Four. Medical Expenses

The scope and intricacies of the tax code's definition of medical expenses take center stage when we deal with the distinctive expenses that people with disabilities incur.

The presence or absence of a disability has no bearing on the procedures we use to compute our deduction. Medical care expenses that exceed 7.5 percent of adjusted gross income (AGI) are deductible as itemized deductions on our tax returns. In order to itemize, the total deductions from all categories, including medical care, must exceed the amount of the standard deduction. Thus, even when an expense qualifies as medical care, its actual deductibility depends on meeting two conditions: Do we have enough itemized deductions from this and other sources to itemize; and do we have enough medical care expenses to get over the 7.5 percent of AGI deductibility threshold? These two questions are linked because in assessing our total itemized deductions, only those health care costs exceeding the 7.5 percent are included in the calculation...

People with disabilities incur many costs that others do not. They may need to purchase assistive technology devices, or rehabilitation, personal assistance, or other services. They may pay heightened costs for transportation; they may need to modify their homes to make them accessible; or they may incur any number of other costs that result from the interplay between the disability and their attempts to reduce its impact on their lives...

Legal Basis for Deductibility

The deduction for "Medical, Dental, etc. Expenses" is set forth in Section 213 of the Internal Revenue Code. Subsection (d) provides the definition of medical care. It includes amounts paid "for the diagnosis, cure, mitigation, treatment or prevention of disease or for the purpose of affecting any structure or function of the body."

For people with disabilities, the key words in this definition are *mitigation* and *for the purpose of affecting any structure or function of the body*. What do these words mean, and why are they so important?

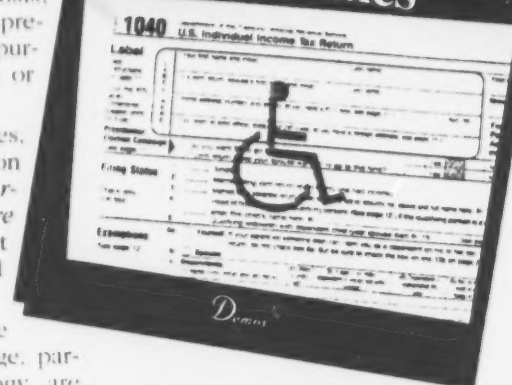
...the implications of the "structure or function" language, particularly for assistive technology, are more profound than may be immediately apparent.

To understand these implications, we must think about the nature and purposes of disability-related costs. The majority of disability-related costs that people incur do not result from attempts to cure or treat illness. People with disabilities are no more or no less ill than anyone else. What disability-related costs more typically involve is the effort to cope with the functional consequences of the impairment, the effort to find alternative strategies for performing various activities and tasks, and to achieve a level of function that minimizes the effects of the disability on the quality and opportunities of life. In common parlance, many, if not most, of the disability-related costs that people incur represent the attempt to compensate for the effects of the functional impairment.

For these expenses, *mitigation* is the key word in the law. Many people concentrate their efforts on seeking a cure, but for growing numbers of people, getting on the day-to-day business of living represents their central and overriding concern.

When the statute speaks of mitigation, it does not refer only to medical improvement, although those are the terms in which many people still instinctively respond. It connotes something broader: mitigation of the functional consequences of the disease or,

Steven B. Mendelsohn Tax Options And Strategies For People With Disabilities



in this case, of the impairment.

We mitigate the impairment of one or another function or structure of the body when we:

- obtain a guide dog or a van lift to facilitate our mobility;
- purchase a closed-caption decoder to facilitate access to the audio portion of TV broadcasts;
- obtain an environmental control system to operate devices and appliances we can not reach or manipulate manually;
- pay for the training and technical support necessary to utilize any of these resources.

Mitigation of functional impairments is the legal logic underlying the characterization of these and similar costs as health care expenses. Each of these measures affects a function or structure of the body. This is the hook on which their deductibility is hung...

Mitigating the effects of a disability by providing alternative methods of function achieves the same practical result as restoration of the function by traditional medical means...

Assistive Technology Devices and Other Goods

Our medical care expenditures may be divided into two categories: goods (tangible things that we buy) and services (the time, expertise, skills, or actions of others). The medical care deduction embraces both types.

The deductibility of goods and services interact in several ways. Sometimes goods will only be deductible if recommended by a physician or other credentialed health care provider. Pharmaceuticals are the best illustration of this category of goods. Since drugs are deductible only when prescribed, a physician's services will be indispensable to their deductibility. Other times, the health professional's diagnosis or recommendations, while not a legal prerequisite to deductibility, constitute powerful evidence of the nature and purpose of the expense. With goods and services alike, their source, nature, and purposes form the continuum along which deductibility is determined.

People with disabilities purchase many of the same items that anyone else uses. Tax issues arise when the cost is for a disability-related item. What are disability-related expenditures? Disability-related items may be divided into three groups: items designed or modified specifically for use by an individual with a disability; items in common use that acquire their significance through some unique functional capacity they confer on the user with a disability; and

items that combine common use and specially designed components.

A hearing aid illustrates the first type, since no one would wear one in the absence of a hearing impairment. A magic marker is a simple example of the second type, since its thick and heavy lines may be the only technique available for making handwriting legible to a person with a visual impairment. For the individual who finds this use for it, the felt-tipped pen becomes an item of assistive technology by reason of the circumstances surrounding its selection and use.

The third category of goods is composed of devices or supplies that are partly specialized and partly mainstream. Consider a standard automobile equipped with hand controls. The automobile itself is standard, but the add-on hand controls are designed for use by a person with a physical disability. Among categories of this *mixed-type technology*, computer systems that include standard hardware plus specially-designed peripherals or software, such as a computer equipped with a speech synthesizer for use by a blind person, are becoming increasingly common.

No standard tax nomenclature yet

exists to describe or distinguish these three categories of devices. We will refer to dedicated devices, that is devices designed specifically for use by people with disabilities, as *special items*. Equipment not ordinarily used in any disability-related way we will call *ordinary or personal use items*. Devices or systems comprised of both special and ordinary components we shall term *mixed type* or *mixed systems*. This terminology comes as close as possible to the relevant tax law language.

In claiming deductions, taxpayers have the simplest task with special items. If the nature and features of such devices are sufficiently explained, no one would seriously contend that their purpose was other than mitigation of the impact of a disability or that they did not affect a structure or function of the body. On this basis, deductibility has been accorded to such purchases as:

- guide dogs and hearing dogs and other service animals;
- telecommunications devices for the deaf (TDDs);
- closed-caption TV decoders;
- equipment to facilitate reading and writing by a person losing sight; and

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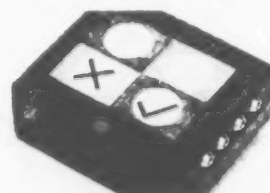
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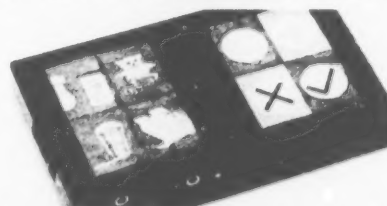
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•hand controls and lift equipment for motor vehicle operation and access.

The list of special items that have been accorded deductibility may seem short. Although a vast array of devices meet the definition of special items, only a tiny fraction of these have been the subject of court decisions or administrative rulings. This could mean either that people are not seeking deductions for such goods or that the IRS is granting deductions when claimed. Based on anecdotal evidence from many taxpayers with disabilities, we believe it means a little of both.

Even if litigation over special items were common, the law could never keep pace with the rapid proliferation of such new technology. Thus, taxpayers must always extrapolate from what has already been decided to the facts of their own cases...

...The ordinary home computer is probably the best example of a personal use item that becomes disability-related because of how it is used. Mixed-system cases which frequently involve the personal computer as their ordinary component present the most vexing problems here. All the issues of proof that we have discussed are involved in securing its deductibility. Since a computer can be used for many purposes by any member of the household, how can you prove that it was purchased and used to meet a disability-related need? Moreover, what is the nature of such a need? Under what circumstances does a computer mitigate a functional disability, and what medical or other evidence would document this role?

Depending on the circumstances, there may be several ways to assemble and prove the key facts. Perhaps the purchase of a computer was recommended by a rehabilitation services agency, by an assistive technology service provider, or even by a physician. Perhaps the particular model chosen was dictated by its interface capabilities with specialized peripherals or adaptive software. Maybe the computer was bought as part of a turnkey system along with adaptive components. Possibly the family already had a computer that the individual with the disability was unable to use. Maybe features that nondisabled users would need were removed or omitted, such as the monitor in the case of a computer bought by a blind user,

Perhaps only specialized software was purchased for use with the machine, making its use awkward or impossible for a person without the disability...

When you stop to analyze them, the possibilities are virtually limitless. If you purchased the computer to compensate for a disability, some facts that will help prove it are bound to exist!

What is the disability-related need that gives rise to the purchase of a computer? In mixed-system situations, this is often the major hurdle. The difficulties associated with showing such a need are illustrated in the law's treatment of the automobile. Although the specialized hand controls for driving it and the wheelchair lift for entering and leaving it are now routinely includable under the definition of medical expenses, the car itself is not deductible. This is because the disability does not give rise to the need for the car; in most places in this country, a car is a practical necessity whether one is disabled or not. From the tax law standpoint, the hand controls or wheelchair lift qualify as medical care expenses precisely because they permit access to and use of the motor vehicle.

The same logic applies to specialized hardware peripherals or software used by people with various disabilities to access and use the home computer. After all, it is not the computer that mitigates the disability, but the specialized access tools that do so by giving us access to and use of it. For the vehicle or computer to be deductible, something more needs to be shown. In their attempts to show this something more, taxpayers have adopted various approaches. Under the current state of the law, none is entirely satisfactory for showing the necessary connection between the personal use item in question and its role in overcoming a disability.

The most compelling case for the deductibility of mainstream equipment is presented by an individual who uses a standard computer to drive an environmental control unit (ECU) to turn on lights, open and close doors, access the telephone, or activate kitchen and other appliances. The ECU, which functions with a computer at its core, is the only means by which these functions can be independently performed, the only source of control over one's physical environment. Use of the ECU system is not a matter of

marginal preference or relative convenience; it makes the difference between being able and unable to perform a number of basic life functions.

...At one time the IRS and the tax court tended to look not only at whether the items in question helped to overcome the effects of a disability, but also at what structure or function of the body the taxpayer intended to affect. Using this line of reasoning, a deduction was sometimes denied because an item was used to meet a personal rather than a medical need, because it was acquired for the convenience rather than the treatment of the taxpayer, or because the live activities and bodily functions to which the item contributed were not basic or important enough. Fortunately, those days seem long behind us. As one court put it, the functions to be ameliorated need not be limited to eating, sleeping, and going to the bathroom.

Thus, it is now clear that efforts to mitigate functional limitations can qualify for the medical expense deduction, whatever function or structure of the body is involved. This has been made especially clear in home modification cases. For example, deduction has been allowed for enclosing the passageway between garage and house so a taxpayer with a serious mobility impairment would not be exposed to the difficulty and potential danger walking on ice entailed. Similarly, another tax payer with a serious disability was granted a deduction for equipment to facilitate his movement from one part to the other of his split-level property. Obviously, going between house and car or between levels of one's property are not major life activities, but the mobility that underlies one's capacity to do them is.

When an expense is deductible, certain related costs are also likely to be deductible. If a device or appliance is deductible, the costs of its upkeep and maintenance are also deductible. This comes into play with service contracts on equipment and with other maintenance and repair costs. Supplies necessary to operate a deductible device, such as batteries, paper and the like, also qualify for deduction. However, follow-up costs are deductible only as long as the need for the equipment continues. ■

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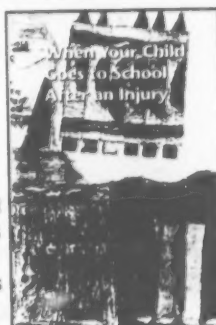
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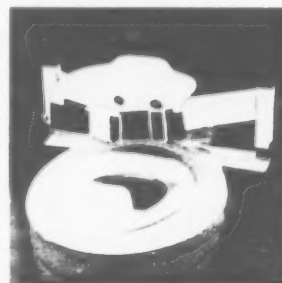
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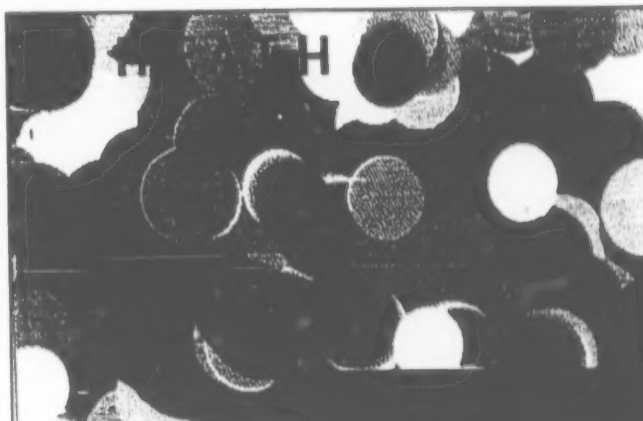
COLUMBIA

Heather Moore, a 19-year-old who is non-verbal due to cerebral palsy, has become a pioneer of sorts. Heather, and other students with multiple disabilities, are participating in a pilot telecommunications project sponsored by British Telecom, Inc. The project electronically links Heather and her schoolmates in Paramus, New Jersey, with a group of students at the Ethel Davis School in London who have similar disabilities.

Bowley and Sophia Moore, Heather's parents, were distressed by her frustration at being unable to communicate. Three years ago, they set out to find ways that technology could help her. Their efforts led to the establishment of this unique project. Heather now uses an electronic speech synthesizer to speak, and an adapted keyboard and software to communicate with her London penpals via electronic mail.

Project participants first "met" through several video teleconferences. As computer access was achieved for each student, electronic mail began crossing the Atlantic. Finally, in October of 1992, a group of U.S. students visited their penpals in London. And one year later, the British students visited New Jersey.

On this page, a few of the program participants share their thoughts—and original computer artwork—with project sponsor British Telecom.



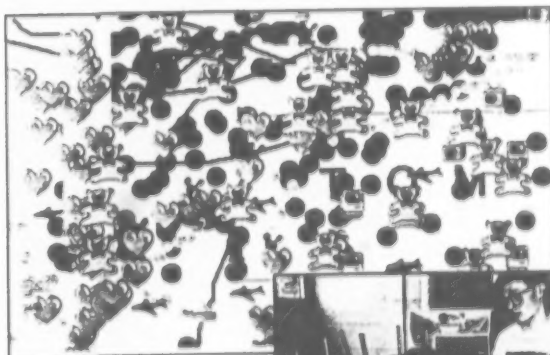
Dear British Telecom,
Thank you for the teleconferences. After meeting Sophina in England, it was nice to see her again. I really liked the British Telecom party in London, the Parliament and the whole trip.

I like writing letters on the computer to my penpal Sophina.

Love, Heather



Heather uses an Apple Macintosh computer with an expanded keyboard and keyguard.



Tom types a message observed by program participant Bob (standing) and program aide Chris (sitting). Chris, like other volunteer aides, is the sibling of a program participant. Sibling aides enjoyed helping program participants gain access to computers, and also developed computer skills and international penpal relationships of their own.



Dear British Telecom,
Thank you for sponsoring this class. I had a great time at computer class this year. I did a lot of fun things. My favorite was typing to my penpal.

Thank you, Tom



Dear British Telecom,
Thank you for letting us use the computers. I like writing letters to Rita and getting the news from England.

Love, Tonielle

Tonielle uses an Apple Macintosh computer with a knee switch and scanning program which displays keyboard choices on the screen and highlights them one-by-one. Tonielle writes messages by pressing her knee switch when the letter she wants is highlighted. This has the same effect as pressing that key on the regular keyboard.

Software Buyers' Guide

Dino-Games: Single switch software for IBM and compatible PCs. Four colorful animated games provide scanning practice; teach cause & effect; directionality; matching by color, shape & orientation; & problem solving. Call for catalog (800) 842-2357.
Great Stocking Stuffer! Academic Software, Inc. 331 W. Second St. Lexington, KY 40507.

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Access Unlimited, 3535 Briarpark Dr., Ste. 102, Houston, TX 77042-5235. (800) 848-0311/Fax (713) 781-3550.

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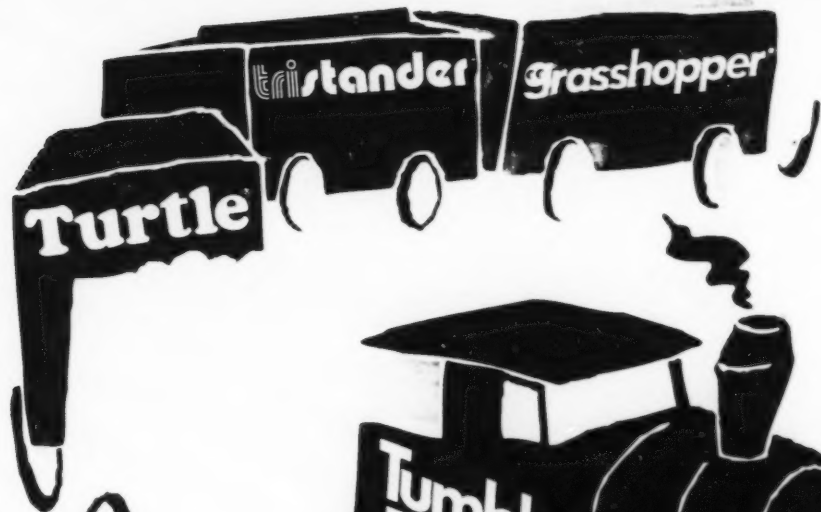
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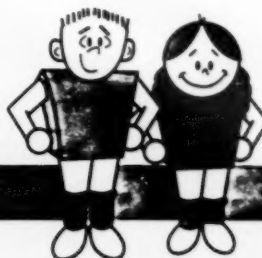
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